

WILD EMPOWERMENT:  
INTERSECTIONAL EXPERIENCES OF IDENTITY AND EMPOWERMENT IN  
WOMEN ACTIVISTS WITH DISABILITIES FROM ACROSS THE WORLD

by

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## DISSERTATION ABSTRACT

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Title: WILD Empowerment: Intersectional Experiences of Identity and Empowerment in Women Activists with Disabilities from Across the World

Various policies and programs across the world, such as the United Nation's Convention on the Rights of Persons with Disabilities, have identified the goal of advancing the empowerment of women and girls with disabilities—a very diverse population. Thus the purposes of this study were to explore the empowerment experiences and salient identities of women activists with disabilities in relation to their environmental contexts. The ecological model of human development, intersectionality theory, and a disability theory of complex embodiment served as conceptual frameworks for this exploration.

Participant recruitment took place during the 2013 Women's Institute on Leadership and Disability (WILD), a program organized by Mobility International USA and sponsored by the United States Agency of International Development. Twenty one participants, who held some form of Deaf/disability, woman, and activist identities, agreed to share their identity and empowerment stories in initial and follow-up interviews. Constructivist grounded theory methods guided a qualitative analysis of the interview transcripts.

Results included (a) participants' individual stories with attention to their intersecting, salient identities, (b) an overview of the empowerment journey, which included participants' focuses on awareness, barriers, and supports, c) participants' core values and strategies for approaching empowerment, and (d) their experiences of empowerment on internal, relational, behavioral, and environmental levels. The discussion includes reflections on the themes of awareness, values, spirituality, and effort, as well as on the choices that participants made about how to present their disability identities and about when to practice adaptability, advocacy, resistance, and acceptance. Most prominently, results suggested that empowerment requires supportive contexts, the removal of barriers, and the restructuring of oppressive systems.

Recommendations for future research and activism include (a) involving more women with disabilities from the Global South in all stages of research and activism; (b) studying the organizational empowerment of Deaf and disability activist organizations; (c) better incorporating indigenous, spiritual, and other knowledge traditions relevant to specific communities; (d) raising awareness and changing attitudes about disability; (e) focusing on barrier removal; (f) attuning to culture in program design and delivery; and (g) promoting distributive justice and power sharing with vulnerable populations.

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In Memory of Alë Mena.

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# **CHAPTER I**

## **INTRODUCTION**

Various policies and programs across the world have identified the goal of empowering women with disabilities. In 2006, for example, the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) recognized that “women and girls with disabilities are subject to multiple discrimination” and articulated an obligation to “take all appropriate measures to ensure the full development, advancement and empowerment of women [with disabilities], for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention” (Office of the United Nations High Commissioner for Human Rights, 1996-2016a, art. 6, brackets mine). As of January, 2017, 160 countries had signed and 174 countries had formally confirmed their commitment to the CRPD (United Nations Treaty Collection, 2017). The United States Senate, however, voted not to ratify the CRPD on December 4, 2012, because many senators considered the Americans with Disabilities Act to be a sufficient commitment to disability rights (Jacobson, 2012). Even so, as more national and international policies and programs emerge with the goal of increasing the development, advancement, and empowerment of women and girls with disabilities, researchers, practitioners, and program evaluators need to clarify and promote a more nuanced understanding of the features of empowerment and how it operates.

In this dissertation, therefore, I sought to explore the self-defined empowerment experiences of participants who identified as women with disabilities from across the world and to understand their experiences in the context of their unique identities and



environments. In doing so, I briefly traveled alongside the women who attended Mobility International USA's (MIUSA's) 2013 seventh international Women's Institute on Leadership and Disability (WILD) and learned from these women. From beginning to end, the journey has been an informative, touching, and humbling one.

The current chapter introduces my dissertation by describing the theoretical and personal underpinnings of the research. The chapter begins by outlining the conceptual frameworks that structured the design, procedures, and analyses of the current study. It then turns to an annunciation of my research approach, which includes information about my salient, intersecting identities, about some of the terminology I use in my writing, and about the origins of this research project. Finally, the chapter outlines the study objectives and research questions that guided my inquiry and provides a road map for the coming chapters.

### **Overlapping Conceptual Frameworks**

One important and difficult aspiration that I had as I imagined the current study was to acknowledge and articulate the complex, dynamic, and situated aspects of each participant's salient identities and empowerment experiences. Thus, I needed frameworks that would help me to organize and discuss the many overlapping aspects of participants' experiential and environmental realities and the relationships among them. I chose, therefore, to utilize the ecological model of human development (Bronfenbrenner, 1989), intersectionality theory (Crenshaw, 1989), and Siebers's (2008) theory of disability and complex embodiment as frameworks to help me organize my thinking about participants' experiences of themselves, others, and their environments. These frameworks portray individuals as living in complex, ever-changing bodies that interact with a multitude of

overlapping material and social environments—a constant interaction that produces human experience.

**Ecological systems theory.** I considered Bronfenbrenner's (1989) ecological theory of human development as a useful backdrop to participants' accounts of empowerment and identity. Bronfenbrenner described each individual as developing in the context of many relationships and overlapping environmental systems. The ecological theory of human development includes three tenets: (a) individuals and their environments continuously interact and mutually influence one another as they change and evolve, (b) individuals actively participate in their development and have the potential to exert influence and power within their environments, and (c) changes in any ecological system may bring about changes in other systems both proximal and distal to the individuals who experience their effects.

In this ecological model of human development, Bronfenbrenner (1989) plotted and defined ecological systems to which researchers and practitioners can attend, including micro-, meso-, exo-, macro-, and chrono- (historical) systems. The microsystem consists of the physical and social environments with which an individual interacts directly, such as that person's family, school, religious community, and/or work place. The mesosystem involves the areas of overlap between an individual's different microsystemic environments—e.g., the interactions between that person's family and school. The exosystem refers to interactions between settings in which the individual is not necessarily involved directly, such as the local political environment, and an individual's microsystem, such as that person's workplace or neighborhood. For example, even if a woman with a disability does not directly participate in her local

political environment, the distribution of resources and local implementation of disability-related policies have a direct impact on the physical and social accessibility that she encounters at work or within her neighborhood. The macrosystem refers to the large-scale sociopolitical contexts in which exosystems, mesosystems, microsystems, and individuals exist. Among other phenomena, the macrosystem contains national, regional, and global economies; infrastructure; cultural values, attitudes, and beliefs; and institutional acts of bias and discrimination. Macrosystemic influences ripple all throughout an individual's social ecology. Finally, the chronosystem involves historic events and personal experiences that have an impact on the individual over time. Such events can be external, such as living through a war or beginning school, or internal, such as surviving a significant illness.

The ecological model (Bronfenbrenner, 1989) offers a helpful framework and important vocabulary for studying a person's development. As I review in Chapter II, many scholars have conceptualized empowerment and identity as processes that change or develop over time. I hoped, therefore, that investigating empowerment and identity processes within the structure of the ecological model would provide essential information to understanding how participants have experienced empowerment and conceptualized their salient identities within various contexts over time.

Although it offers many benefits, the ecological model (Bronfenbrenner, 1989) is complex, extensive, and difficult to apply comprehensively to one research project. For this reason, many researchers have tended to choose a few systemic spheres in which to examine their data (e.g., family, community, sexism, and/or law and policy). In the current study, however, I did not identify particular systems to explore at the outset.

Rather, I sought to identify and investigate some of the systems that the participants, themselves, referenced as important to their experiences. I may have, therefore, sacrificed analytical depth for the sake of following and exploring the breadth of participants' life stories.

**Intersectionality theory.** Intersectionality theory is a second lens that I used to examine empowerment and identity salience. Intersectionality as an analytic tool has a long history of use across the world (Collins & Bilge, 2016). In the United States, African-American women activists and scholars (e.g., Collins, 2000; Crenshaw, 1989, 1991) popularized the concept by critiquing the ethnocentric biases of feminist theories and activism and the androcentrism of race studies and antiracist movements (Cole, 2009; Hankivsky et al., 2010; Mullings & Schulz, 2010). Intersectionality refers to an analytic approach that simultaneously examines the meanings and consequences of multiple categories of identity, difference, power, and privilege, as well as the ways in which they mutually constitute one another (Cole, 2008, 2009; Crenshaw, 1989, 1991; Hankivsky, de Leeuw, Lee, Vissandjee, & Khanlou, 2011; Schulz & Mullings, 2010). Crenshaw (1989) offered a helpful analogy:

Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars traveling from any number of directions and, sometimes, from all of them. (Crenshaw, 1989, p. 149)

Intersectional analyses include some key assumptions and core themes.

Assumptions include (a) different dimensions of a person's identity cannot be separated from one another; (b) one type of social identity, such as gender, is not inherently more important than any other identity; and (c) essentializing categories—e.g., assuming that

all women share the same experiences in spite of their different ages, ethnicities, disabilities, social classes, national/cultural contexts, etc.—is a mistake (Hankivsky et al., 2010). Collins and Bilge (2016) identified six core ideas that arise when people use intersectionality as an analytic tool: “inequality, relationality, power, social context, complexity, and social justice” (p. 25). In other words, intersectional analyses involve the consideration of cultural and political histories of multiple groups, of the ways that these socially constructed categories depend on one another for meaning, and of their complex associations with individual wellbeing and social phenomena (Cole, 2009). For example, Crenshaw (1994) used intersectionality to frame interactions between patriarchal and racist forces in the context of violence against women of color, who live “within overlapping systems of subordination and at the margins of feminism and anti-racism” (p. 21).

Dhamoon and Hankivsky (2011) outlined various focuses for intersectional analyses, two of which apply to the current study. One potential focus that they recommended was exploring the identities of a set of individuals who belong to several marginalized social groups. In the current exploration, I worked with participants from the Global South who claimed variations of Deaf/disability, woman, and activist identities (read “A note on language” later in this chapter). Dhamoon and Hankivsky explained that the researcher’s analyses should involve the social location—the practical, everyday disadvantages and privileges—that participants share as well as the heterogeneity that exists at this social location or point of intersection. Another potential focus that they suggested was attending to the systems of domination that affect participants’ empowerment and wellbeing. Some examples in the current study included

colonialism, sexism, ableism, audism, and oralism. When exploring systems of domination (i.e., macrosystemic variables), Dhamoon and Hankivsky encouraged intersectionality researchers to investigate how society privileges certain norms and thus certain people over others. The researcher focuses on the many manifestations of otherness, on what intersections/interactions elucidate about power, and on analyzing the techniques of power.

Although intersectionality theory arose to address the lived experiences and critiques of people at the convergence of multiple stigmatized identities, it can also serve as an analytical framework for considering the experiences of anyone with multiple identities that represent a complex mixture of privilege and disprivilege, empowerment and disempowerment (Cole, 2009). The participants in this dissertation shared some form of Deaf/disability, woman, and Global South nation identifiers—categorization labels that utterly fail to capture their diversity and that place them at an intersection of marginalization experiences. They also carried a variety of national/cultural, religious/spiritual, social class, caste, education, professional, and activist identities that were salient to them and that offered a range of power and privilege to their different experiences. Similar to my approach in using the ecological model, I cast my net widely to investigate unique aspects of participants' salient identities, not just the Deaf/disability, woman, and Global South nation identifiers that they shared.

Whether in the context of research, counseling and psychotherapy, or program design and implementation, using intersectional analyses that resist the use of separate, dichotomous, hierarchical variables can aid in the consideration not only of human diversity but also of power dynamics (Hankivsky et al., 2010). Cole (2008) pointed out

that political agendas are often set by people whose intersecting identities represent more privilege, status, and resources than the identities of the people they serve; by not considering intersectionality and power dynamics, movements or organizations run the risk of contributing to the secondary marginalization of the very people whose causes they seek to champion. To minimize this risk, I sought to explore empowerment in the context of participants' intersecting social and cultural locations and simultaneously remain aware of my own. Generally, much as in the current study, researchers using intersectional analyses have tended to work with a variety of stakeholders, such as policy makers, grassroots activists, and multiply-oppressed communities, to bring about shifts in power and work toward social justice (Hankivsky et al., 2010). Empowerment, the primary focus of the current study, is itself a process that involves power shifts in the service of social justice and thus fits well into an intersectionality framework. "Intersectionality is not simply a method for doing research but is also a tool for empowering people" (Collins & Bilge, 2016, p. 37).

Some drawbacks of using intersectionality frameworks are inevitable, however. Although some scholars have claimed that intersectionality can be applied to many existing research methods (Cole, 2009; Dhamoon & Hankivsky, 2011), theoretically informed and methodologically sound approaches to applying intersectional frameworks are still in their early stages (Dhamoon & Hankivsky, 2011; Hankivsky et al., 2010; McCall, 2005). Dhamoon and Hankivsky (2011) argued that, even when researchers analyze multiple aspects of identity together, they still risk essentializing aspects of identity by overgeneralizing their findings or by inadequately accounting for participants' self-described identities. They went on to explain that using an intersectionality

framework is extremely complicated due to (a) the multi-dimensional ways in which power operates and interacts with subjectivity, subjection, and social location; (b) the different ecological levels at which interactions occur; and (c) the differing degrees and forms of penalty and privilege among social locations and subjects. In other words, doing intersectionality well is difficult, especially for a researcher like myself with many sociopolitical privileges. Garland-Thomson (2017) stated that “The most compelling and complex analyses of gender intersectionality take into consideration what I call the ability/disability system—along with race, ethnicity, sexuality, and class” (p. 360). I turn, therefore, to a theory of disability to help sharpen my focus.

**Disability studies and the theory of complex embodiment.** In the field of disability studies, Siebers’s (2008) disability theory encompasses the importance of one’s embodied and material realities, as well as the effects of linguistic, social, and political representation. Some concepts important to this theory include complex embodiment, identity, and the ideology of ability.

The theory of complex embodiment (Siebers, 2008) simultaneously emphasizes the roles of exclusionary environments and bodily realities in contributing to people’s lived experiences of disability. According to this theory, disabilities exist within a spectrum of human variation—as part of the variability among individuals and within individual life spans—and are thus in constant dialog with social forces. The relationship between the body and social representations is “reciprocal” and “mutually transformative” (p. 25). In other words, linguistic systems and social representations play a role in constructing our body-minds. Simultaneously, the lived experiences of our body-



minds, which are just as “vital and chaotic” (p. 26) as linguistic and social systems, play a reciprocal role in constructing our language and society.

Siebers (2008) classified identity as “an embodied representational category” (pp. 2-3) and defined disability as a cultural and minority identity, which is subject to social forces and capable of bringing about social change. Siebers argued that “Disability as an identity is never negative. . . . As a condition of bodies and minds, however, disability has both positive and negative valences” (p. 4). In this dissertation, I consistently discuss disability as a positive identity that makes positive contributions to society while I simultaneously relay the valent range of embodied and social experiences that participants described in relation to disability.

The ideology of ability—what Goodley (2017) called the ideology of ableism—is a major social force that Siebers (2008) discussed in reference to disability and other marginalized identities. The ideology of ability is, in the most general terms, “the preference for able-bodiedness” (Siebers, 2008, p. 8), which influences social values, judgements, and even definitions about human beings across the world. When values, judgements, and definitions about humanness are based on an ideology of ability, then this ideology has a direct impact on human rights. Siebers explained, “All known theories of human rights, whether based on humanity, social contract theory, utilitarianism, or citizenship, exclude individuals from the rights-bearing community if they do not possess the specific abilities required for membership” (p. 178). People with disabilities have certainly been denied their human rights based on this ideology of ability, but so too have people who hold many other marginalized identities (Baynton, 2017; Garland-Thomson, 2017; Longmore & Umansky, 2001). Whenever the language of deficit and pathology

labels people from an identity group as inferior to others, the ideology of ability is at play, contributing to discrimination, segregation, institutionalization, and other forms of injustice.

As a conceptual framework, Siebers's (2008) theory of disability and complex embodiment offers a great deal to a contextual and intersectional exploration of empowerment and identity. Like the ecological model (Bronfenbrenner, 1989), complex embodiment integrates biological, sociopolitical, historical, and other environmental forces in identifying the influences on a person's lived experiences. Complex embodiment and intersectionality theory are also complementary in that they both address the mechanisms by which identities reciprocally construct one another (Collins, 2000; Siebers, 2008). Within intersectionality theory, Siebers (2008) emphasized (a) that identities are complex embodiments in addition to perspectives or situated knowledges and (b) that the ideology of ability is intersectional and useful to consider when examining multiple systems of oppression. In reference to the ideology of ability, Siebers wrote,

[Disability] functions at this historical moment according to a symbolic mode different from other representations of minority difference. It is as if disability operates symbolically as an othering other. It represents a diacritical marker of difference that secures inferior, marginal, or minority status, while not having its presence as a marker acknowledged in the process. (p. 6, brackets mine)

In other words, taking an embodied, disability-aware stance might offer a unique advantage to a study of identity and power.

A disadvantage of using a theory of disability and complex embodiment (Siebers, 2008) as a conceptual framework is that it derives from the field of disability studies, which, as a discipline, is historically rooted in unexamined whiteness (Bell, 2017) and in

perspectives from the Global North (Grech, 2011, 2015; Grech & Soldatic, 2015; Meekosha & Shuttleworth, 2017). As Bell (2017) expressed so succinctly: “Disability Studies in its current incarnation *is* White Disability Studies” (p. 414). The ideology of whiteness can operate as covertly as the ideology of ability. Indeed, Smith (2004) suggested that “It is also likely, given the normative universalization of whiteness in modernist Western culture, that the construction of whiteness is at the complex, multiple roots of both racisms and ableisms” (“What Does Whiteness Studies,” para. 12). Grech (2011) observed that “the views and tenets of the Western disability studies are exported to the majority world backed by a discourse of inferences, generalizations and myths” (p. 87). As a white, United States-born researcher and activist, therefore, I need to, at the very least, follow Bell’s (2017) suggestion and acknowledge definitively and accurately that whiteness has affected my research at every stage of the research process. I am also committed to continue raising my awareness of how the ideologies of whiteness and ability operate in my investigation of power and intersecting identities and to subvert these ideologies as best I can.

### **Annunciation and Conscientization of the Researcher**

Drawing from the work of Paulo Freire, I. Prilleltensky (1989) encouraged psychologists to engage in conscientization and annunciation. Conscientization is the ongoing process of increasing one’s awareness of the socioeconomic and cultural circumstances that shape one’s life and of one’s capacity to transform this reality. Annunciation is the act of declaring one’s values and assumptions as best one can and exploring how they inform one’s moral discourse and practices. I agree with I Prilleltensky that the research and practice of psychology is not value neutral, apolitical,

or objective and that our values and assumptions matter. Thus I briefly share my personal and cultural background, my professional values, and the assumptions that underlie my research practices.

**Personal background.** My perspective, research, and writing arise from my individual history and unique social location. I identify as a United States-born, white, sick and disabled person of mixed European and indigenous Mexican ancestry. While I present as a blind woman, I identify as nonbinary and experience nonapparent disabilities. I have entered a privileged, educated social class, and I speak and write English fluently and Spanish at an intermediate level.

My thinking and scholarship have shifted considerably over the years. I began my undergraduate education with a relatively unquestioning acceptance of patriarchal, ethnocentric, normative, and positivist epistemologies, of discrete and essentialized categories, and of a medical model of disability and mental health (a model discussed in greater detail in Chapter II). As an adult, my encounters with negative biases, discrimination, disability access barriers, and invalidations of my lived experiences, combined with my reflections on the experiences of colleagues and therapy clients, prompted me, thankfully, to reach toward disability studies, which continues to protect me from a despairing sense of loneliness and disillusionment with academia and with my chosen field of psychology. Although I am still regularly subject to unwelcome intellectual habits, I seek out the aspects of counseling psychology that guide and encourage me to question colonizing discourses, expose underlying normative assumptions, examine contexts and social constructions, engage in reflexive processes that explore my own interactions with privilege and oppression, and resist systemic

injustice. I now understand disability and neurodiversity as valuable forms of human variability that exist in constant interaction with material and social environments. My appreciation of disability coexists, however, with the awareness that many body-minds across the world are injured, sickened, and impaired by the impacts of neoliberal globalization or neocolonialism—impacts that include poverty, industrial pollution, extraction of resources, exploitative labor, and war. Although my intellect is still forming in accordance with my values and the language I use continues to steep in the very injustice I want to oppose, I offer this dissertation as a snapshot of my evolving work toward cross-cultural, social-justice-oriented scholarship and activism.

**A note on language.** According to the theoretical frames I've adopted for this study, language is embedded, entangled, and in complex interaction with bodies, identities, power, and material and social contexts. I reflect here on some of the choices I have made regarding terminology in my writing. Specifically, I discuss some language pertaining to gender, region, disability, and deafness/Deafhood.

Participants in the current exploration self-identified as women in a manner consistent with a cisgender definition (refer to Trans Student Educational Resources, 2018). For the most part, I use the term women to refer to participants and to the unspecified category of women used by international organizations, such as the UN. In doing so, I do not intend to endorse a gender binary.

People in academic and global policy circles, including at the UN, have begun using the term Global South with more frequency (Dados & Connell, 2012; Wolvers, Tappe, Salverda, & Schwarz, 2015). The term typically refers to countries that face social, political, and economic challenges, such as poverty, environmental degradation,

human and civil rights abuses, ethnic and regional conflicts, mass displacements of refugees, hunger, and disease (Ming'ate, 2015). Adding the word Global is meant to clarify that the term South does not refer strictly to a geographical categorization of the world but, instead, to a categorization that reflects economic inequalities, geopolitical power relations, and other global processes and structures (Dados & Connell, 2012; Rigg, 2015). Like Goodley (2017), “I remain mindful of the complexity of these terms, aware that it is possible to find Global North localities in Global South contexts (and vice versa)” (p. 45). Some scholars believe the Global North-South terminology to be particularly empowering and effective in resisting hegemonic forces because it is intended to minimize the hierarchy that previous categorical terms implied (Duck, 2015; Mendez, 2015). Others criticize the term for obscuring historical power relations between regions or countries (Magallanes, 2015) or wealth disparities within countries (Eriksen, 2015). Recognizing that it is an imperfect term, I occasionally describe participants in the current exploration as coming from countries in the Global South when I wish to highlight the aspects of their identities and empowerment experiences that relate to the social, political, and economic barriers arising from colonial histories, neocolonial practices, and global capitalism.

Dunn and Andrews (2015) reviewed the evolution of language pertaining to disabilities, focusing particularly on person-first and identity-first constructions. Although the American Psychological Association (APA; 2010) currently recommends person-first language, which identifies the person before the disability (e.g., “person who is blind”), Dunn and Andrews noted that many disability cultural advocates and disability studies scholars use identity-first language, which names the disability first as an

important aspect of identity (e.g., “blind person” or even just “blind”). The authors advocated for the judicious use of identity-first language alongside person-first constructions in academic writing. As a multiply-disabled researcher and cultural advocate who is interested in learning about salient, intersecting identities, I tend toward using identity-first language throughout the rest of this dissertation, unless I am representing a different preference on the part of individual participants or within the organizations that enter into my discussion (e.g., Mobility International, 2017).

Price (2017) reviewed language related to neurodiverse identities and experiences, showing how different terms do different cultural work in particular contexts. Among other identity terms, Price reviewed language around the terms mad, psychiatric consumer/survivor/ex-patient, mental illness, neuroatypical, and mental disability. For the most part, I use the term psychosocial disability throughout the current exploration because (a) it is the term that participants most often used and (b) I like how, as Price wrote, “psychosocial disability announces that it is deeply intertwined with social context, rather than buried in an individual’s brain” (p. 339).

Two major constructions of deafness are currently most prevalent in society—deafness as a category of disability and Deafness as membership in a cultural-linguistic minority group (Lane, 2006). Lane (2006) maintained that these two constructions “compete for shaping deaf peoples’ destinies” (p. 80). Indeed, both constructions occurred in participants’ identity stories and in their descriptions of the empowerment journey. Throughout this dissertation, I try to use the term deaf with a lowercase d to refer to deafness when it is clearly discussed solely as an audiological condition and Deaf

with a capital D to refer to Deafhood (Ladd, 2008) as an identity or culture that has rich linguistic and artistic histories across the world (e.g., Golberg, 2011).

**Research approach.** The current research project arose out of a conversation I had with Cindy Lewis, the Director of Programs at MIUSA, in the fall of 2012. I shared my hope to do something useful with my dissertation and asked if there was anything I could research with and for MIUSA. With her usual acumen, Ms. Lewis pointed to the complex, multifaceted, and illusive nature of empowerment and shared her frustration with the lack of cultural sensitivity (including disability culture) in the existing measures of empowerment. She indicated that gathering information about WILD participants' experiences of empowerment could potentially benefit the continued evolution of the WILD program and perhaps the future construction of more appropriate measures. I was delighted to dive into such a project.

Due to the exploratory and community-based nature of this study, I chose qualitative and participatory research methods to aid me in examining participants' accounts. I sought methods that would facilitate (a) my close attention to participants' self-directed descriptions of their salient identities and empowerment experiences and (b) the generation of rich data sensitive to participants' ecological contexts. One-on-one, responsive interviews and participant observations were my primary sources of data collection during and after the WILD program, and throughout the project, I adapted Charmaz's (2006) constructivist grounded theory to guide my analysis of the themes and conceptual categories in participants' accounts.

Although my theoretical approach is more complicated, for the most part, I designed and conducted the current research within an interpretive/constructivist



paradigm of scientific inquiry (Guba, 1990; Leavy, 2017; Ponterotto, 2005). As demonstrated by the theory of disability and complex embodiment (Siebers, 2008), I tend to think about identity, power, and ontology in general within a theoretical paradigm that accounts for the mutually influential relationships among social and material things (e.g., Schriempf, 2001) and infuses analyses with the emancipatory, communitarian, and transformational values of critical theory (Fox, I. Prilleltensky, & Austin, 2009). That said, the methods of this study primarily reflected an interpretive/constructivist research paradigm insofar as I moved from the assumptions that (a) multiple valid realities exist, (b) knowledge can arise from a subjective interaction between researchers and participants, and (c) seeking to understand the lived experiences of others is a worthy goal (Guba, 1990; Ponterotto, 2005).

### **Purpose and Research Questions**

I would like my dissertation to represent a small effort toward bringing about shifts in power and working toward social justice. I have sought, therefore, to practice the complexity that I believe is necessary in the examination of empowerment processes as they weave into an intricate tapestry of social identities and ecological systems. I also believe that attending to the first-person accounts of people who live amid disempowering conditions and who identify as members of oppressed social groups is essential to any study of empowerment. Thus the purposes of this study were to explore the nature of empowerment processes and begin outlining their relationship to multiple, intersecting identities and overlapping environmental systems, specifically as they pertained to the multinational sample of women activists with disabilities and Deaf

identities who attended MIUSA's Seventh International WILD Program (Mobility International USA, 2013b).

I asked the following two research questions: (a) How would the WILD participants describe their experiences of empowerment within the multiple, overlapping contexts of their lives (e.g., family, school, work, sociopolitical sphere); and (b) How would participants' salient, intersecting identities (e.g., gender, disability, nationality, social class) relate to their empowerment experiences?

Initially, I also included two questions in this project that related to program evaluation: (a) how would participants experience empowerment during the WILD program in Eugene, Oregon; and (b) How would participants sustain their perception of empowerment upon returning to their home countries? Although I collected data to investigate these additional questions, a description and interpretation of these data are beyond the scope of this dissertation and are not included in the current manuscript.

### **Dissertation Roadmap**

For my readers and fellow travelers, I offer a road map of the coming chapters. The next chapter, Chapter II, outlines the need for empowerment research and contains a brief literature review surrounding the constructs of empowerment and identity, which are my main topics of exploration. Chapter III includes the methods that I used to collect and analyze participants' stories. Chapter IV, the first results chapter, consists of depictions and basic conceptualizations of participants' salient, intersecting identities. The second results chapter, Chapter V, contains details of participants' empowerment journeys, focusing particularly on the topics of awareness, barriers, and supports. Chapter VI, the final results chapter, outlines participants' approaches to and various

manifestations of their empowerment. In the concluding chapter of the dissertation, Chapter VII, I discuss the results, their relationship to theory and the research literature, limitations of and other reflections on the study, and implications for further research.

## **CHAPTER II**

### **LITERATURE REVIEW: EMPOWERMENT AND IDENTITY**

Chapter II provides a brief overview of the research literature pertaining to empowerment and identity, drawing from the fields of international development, psychology, and disability, Deaf, and Global South studies. To address the need for advancing empowerment among Deaf and disabled women and girls, the chapter begins with a summary of barriers and of the global movements toward gender and disability equality. The chapter continues with (a) a discussion of power, control, and empowerment processes and outcomes; (b) an exploration of multiple dimensions, levels of analysis, and the role of context in empowerment; and (c) reflections on the paradox of empowerment and on the questions of how and to what extent we can truly contribute to the empowerment of others. Finally, the chapter concludes with a focus on identity, including an overview of (a) identity theories and social identities; (b) Deaf and disability identities and models of disability and Deafhood; (c) identity development models; and (d) multiplicity, intersectionality, and identity salience.

#### **The Need for Empowerment**

Before discussing empowerment and identity as constructs to explore in relation to Deaf and disabled women activists, I set the stage by providing an overview of the barriers that Deaf and disabled women experience across the world and some of the transnational movements toward advancing power and control among women and people with disabilities. I highlight some global concerns pertaining to Deaf and disabled women as identified by various scholars, UN conventions and declarations, and the World Health Organization (WHO), and argue that such concerns demonstrate that populations of Deaf

and disabled women could benefit from increased empowerment across the world.

Although I only offer a brief overview, I hope to identify some of the currently recognized issues of concern prior to relaying participants' own accounts of their individual and community experiences in the results chapters.

**Barriers facing Deaf and disabled women and girls.** United Nations Women (2016) estimated that one in five women lives with disability and that the prevalence of disability for women (19.2%) is higher than for men (12%; read also World Health Organization & World Bank, 2011). Women with disabilities comprise three quarters of the people with disabilities in low and middle-income countries (Human Rights Watch, n.d.), and 65-70% of women with disabilities live in rural areas (World Health Organization & World Bank, 2011). The prevalence of disability is generally increasing worldwide due to an aging population and to chronic health conditions (World Health Organization, 2016; World Health Organization and World Bank, 2011).

"Girls and women of all ages with any form of disability are generally among the more vulnerable and marginalized of society" (United Nations General Assembly, 2000, para. 63). They encounter access and inclusion barriers across physical, institutional, and social environments that prevent their full, equal, and active participation. "These barriers . . . add to the disadvantage customarily experienced by disabled persons belonging to such populations or social groups as women, children, the elderly and refugees" (Secretary-General of the United Nations, 2003-2004, para. 4). Deaf and disabled women and girls who are members of marginalized ethnic, linguistic, religious, or migrant groups or who identify as lesbian, pansexual, transgender, and/or intersex are at particular risk of multiple layers of discrimination (Office of the United Nations High Commissioner for

Human Rights, 2012; Secretary-General of the United Nations, 2017a; United States Agency for International Development, 2017).

Girls and women with disabilities experience a number of physical, institutional, and attitudinal barriers to their participation in society. Due to the stigmas associated with both disability and gender, they are more likely to experience discrimination than nondisabled women or men with disabilities (Office of the United Nations High Commissioner for Human Rights, 1996-2016b). For example, women with disabilities encounter significant barriers in accessing adequate housing and services and are particularly vulnerable to being institutionalized or hidden away in their family homes (Office of the United Nations High Commissioner for Human Rights, 1996-2016c; United Nations Children’s Fund, 2013). Deaf and disabled girls are less likely than boys to receive care and food—including access to safe drinking water and basic sanitation—and are more likely to be left out of family interactions and activities (United Nations Children’s Fund, 2013). Legal barriers and social stigma discourage or prevent women with disabilities from exercising their sexual and reproductive rights—for example, to marry, to have children, or to adopt children (Human Rights Watch, n.d.; Secretary-General of the United Nations, 2017a; World Health Organization & World Bank, 2011).

Women and girls with disabilities are at particular risk—in their homes, in institutions, and in community settings—of experiencing violence, injury, abuse, restraint, negligence, and exploitation (Office of the United Nations High Commissioner for Human Rights, 1996-2016a; United Nations Children’s Fund, 2013). They may experience abuse at the hands of their families, personal assistants, classmates, coworkers, strangers, peers, and/or the state (Human Rights Watch, n.d.; Office of the

United Nations High Commissioner for Human Rights, 2012). Deaf girls and women and girls and women with visual, intellectual, psychosocial, or multiple disabilities may be especially targeted for abuse because of the belief that communication, information, and attitudinal barriers will prevent them from complaining or accessing help (Human Rights Watch, n.d.; Office of the United Nations High Commissioner for Human Rights, 2012; Secretary-General of the United Nations, 2017a). A transactive nature also exists between violence and intellectual or psychosocial disabilities: women with intellectual and psychosocial disabilities are particularly vulnerable to violence, and women who experience gender discrimination, violence, poverty, armed conflict, and/or displacement are at risk for experiencing delayed development and psychosocial disabilities (United Nations Women, 2009; United Nations Children’s Fund, 2013). Girls and young women with disabilities, particularly intellectual and psychosocial disabilities, are disproportionately subjected to forced contraception, abortion, and sterilization for reasons of eugenics, menstruation management, and pregnancy prevention (Secretary-General of the United Nations, 2017a; United Nations Children’s Fund, 2013; World Health Organization & World Bank, 2011). Women and girls with disabilities are at risk of being trafficked and forced into prostitution and of experiencing early or forced marriage, early pregnancy, and female genital mutilation (Secretary-General of the United Nations, 2017a; United Nations, 2015; United Nations Women, 2016). Furthermore, due to their increased risk of experiencing violence and to their limited access to sexual and reproductive information and health care, women and girls with disabilities face unique challenges in preventing HIV infection (Secretary-General of the

United Nations, 2017a; United Nations Children's Fund, 2013; World Health Organization & World Bank, 2011).

According to the WHO (World Health Organization, 2016; World Health Organization & World Bank, 2011), women with disabilities experience a number of disadvantages with regard to receiving both general and specialized healthcare. Access barriers are prevalent. Some examples include the unaffordability of health services; lack of transportation, particularly in low-income countries; uneven wheelchair access to buildings; inaccessible medical equipment, such as mammography equipment that only accommodates women who stand; lack of sign language interpreters; and a dearth of braille information and signage. Deaf and disabled women also experience a greater vulnerability to HIV/AIDS and to maternal mortality. The lack of appropriate, disability-specific services is another significant barrier to health care in many areas. Moreover, Deaf and disabled women may also experience discrimination in seeking mainstream health services. For example, the WHO (2016) reported that women with disabilities tend to receive less screening for breast and cervical cancers than women without disabilities.

The Secretary-General of the UN (2017b) identified access to education as a major concern for women and girls with disabilities. The Secretary-General reported that women with disabilities receive on average 4.98 years of education, as compared to 5.96 years for men with disabilities and 6.26 years for nondisabled women. Over all, about 41.7% of girls with disabilities complete primary school, as compared to 50.6% of boys with disabilities and 52.9% of nondisabled girls. This educational disadvantage among women and girls with disabilities likely contributes to higher risk of social exclusion and poverty and diminishes their capacities and opportunities to work.



Women with disabilities face many difficulties in entering the open labor market. The Secretary-General of the United Nations (2017b) reported that women with disabilities have an employment rate of 19.6% as compared with 52.8% for men with disabilities and 29.9% for nondisabled women. Largely due to social attitudes and stigma, many women and girls with and without disabilities engage in domestic labor—such as food preparation, cleaning and upkeep of dwellings, laundry, gardening, shopping, and caring for other family members—which tends not to generate monetary income and which places them at higher risk of experiencing poverty (United Nations, 2015). According to the International Labour Organization (O'Reilly, 2003), when women with disabilities secure paid work, they often experience discriminatory hiring and promotion practices, less access to training and retraining, less access to credit and other productive resources, less pay for equal work, occupational segregation, and exclusion from economic decision-making processes.

**Transnational movements to promote equality.** The UN has worked to promote policies that have a positive impact on women across the world. The 1979 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW; United Nations Women, 2009) and the Declaration on the Ending of Violence against Women (DEVAW; United Nations, 1993) have served as social and political guides (e.g., a macro-systemic influence) for rights-based movements toward international gender equality. CEDAW called for equality of outcomes in addition to equality of opportunity, obligating UN member states to go beyond passing anti-discrimination laws and to take necessary steps to ensure that women enjoy equality in their daily lives. At the Millennium Summit in 2000, 189 member countries of the UN recognized that, although

the legal systems of many countries stipulated gender equality and suffrage at the macrosystemic level, the exosystemic implementation of these laws and the realization of gender equity remained elusive throughout the social ecology (United Nations Millennium Project, 2005). In the Millennium Development Goals, UN member countries promoted gender equality and empowerment of women (p. xvi) as another international policy opportunity for countries to mitigate the gender inequity that stemmed from entrenched attitudes, sociopolitical institutions, and market forces (United Nations Millennium Project, 2005).

The UN has also addressed the particular needs and roles of women with disabilities. The World Programme of Action concerning Disabled Persons (United Nations General Assembly, 1982) recognized women with disabilities as a special group and addressed their specific barriers to accessing health care, education, and employment. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations General Assembly, 1994) also identified women with disabilities as needing additional attention in the context of efforts toward achieving equal opportunities for all people with disabilities. The Beijing Declaration and Platform for Action (Fourth World Conference on Women, 1995) raised disability inclusion as important to reducing empowerment barriers faced by all women and girls and outlined specific actions for governments to take to ensure the empowerment of women and girls with disabilities.

Building on previous commitments, the UN's CRPD (Office of the United Nations High Commissioner for Human Rights, 1996-2016a) represented a significant movement forward. The CRPD advocated for a significant shift from viewing people with disabilities as objects of charity, medical treatment, and social separation to

understanding them as human beings who have rights, who can adopt agentive roles in claiming their rights and making informed decisions, and who can serve as active members of society (United Nations Division for Social Policy and Development Disability, 2016). The CRPD (Office of the United Nations High Commissioner for Human Rights, 1996-2016a) acknowledged "the specific cultural and linguistic identity of deaf people, including sign languages and deaf culture" (Art. 30.4) and detailed the aforementioned socioeconomic, safety, health care, communication, information, education, employment, and social barriers that Deaf and disabled women experience. In light of these barriers, the CRPD made a particular commitment to advancing the empowerment of Deaf and disabled women.

After the CRPD (Office of the United Nations High Commissioner for Human Rights, 1996-2016a), the 2030 Agenda for Sustainable Development (United Nations General Assembly, 2015) integrated and included the concerns of people with disabilities. In general, this agenda set sustainable development goals along environmental, economic, and social dimensions and specifically referenced disability in relation to education, growth and employment, inequality, and accessibility of human settlements. The sustainable development goals also required that the ongoing data collection and monitoring of the goals include a closer attention to people with disabilities.

Most recently, the United Nations General Assembly (2017) drafted a resolution entitled "Implementation of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto: situation of women and girls with disabilities." This resolution acknowledged that women and girls with disabilities face barriers in all aspects

of life and focused specifically on (a) multiple and intersecting forms of discrimination; (b) education and employment; (c) access to health services, including sexual and reproductive health; (d) access to justice and equal recognition before the law; and (e) participation in public and political life. With regard to empowerment, the resolution called upon UN member states to:

strengthen efforts to empower women and girls with disabilities and enhance their participation and promote leadership in society through taking measures to address all barriers that prevent or restrict the full and equal participation of women and girls with disabilities, including in the government and public sector, the private sector, civil society and all branches and bodies of the national monitoring system of the Convention, and working to ensure that women and girls with disabilities are closely consulted and actively involved, through their representative organizations, in the design, implementation and monitoring of all legislation, policies and programmes which have an impact on their lives. (para. 26)

### **Empowerment!**

Empowerment is a complex, difficult-to-define construct that arises in theoretical and applied contexts and in a variety of disciplines, including community psychology, education, international development, political theory, sociology, and women and gender studies (Cattaneo & Chapman, 2010; Desai, 2010; Hur, 2006; McWhirter, 1994). In part, empowerment rouses such wide-ranging curiosity because it is multidimensional, transpiring along psychological, sociological, economic, political, and other dimensions (Hur, 2006). Empowerment also occurs on multiple levels, including individual, interpersonal, organizational, community, and collective levels (Hur, 2006; Perkins & Zimmerman, 1995; Rappaport, 1995). Such variation and complexity in the subjects and effects of empowerment have led to a general lack of intra-disciplinary and cross-disciplinary coherence.

In short, the empowerment literature appears daunting and disorganized with many definitions at play and diverging lines of inquiry to explore. The Cornell Empowerment Group (1989), for example, conceptualized empowerment as "an intentional ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources" (p. 2).

McWhirter (1994) described empowerment as

The process by which people, organizations, or groups who are powerless or marginalized (a) become aware of the power dynamics at work in their life context, (b) develop the skills and capacity for gaining some reasonable control over their lives, (c) which they exercise, (d) without infringing on the rights of others, and (e) which coincides with actively supporting the empowerment of others in their community. (p. 12)

Cattaneo and Chapman (2010) defined empowerment as

An iterative process in which a person who lacks power sets a personally meaningful goal oriented toward increasing power, takes action toward that goal, and observes and reflects on the impact of this action, drawing on his or her evolving self-efficacy, knowledge, and competence related to the goal. (p. 647)

The ambiguity and myriad perspectives expressed in the literature have led many people to question whether empowerment is little more than a buzz word (e.g., Strong, 1994), but I believe that we have concentrated so much energy on this concept because it represents a process essential to individual, group, organizational, and community wellbeing.

For the purposes of providing a brief literature review, I explore empowerment theory in terms of (a) power and control, (b) processes and outcomes, (c) individual, collective, and contextual levels of analysis, (d) the need for a more precise definition, and (e) the paradox of empowering or helping others. This organizational format

incorporates the core elements of many proposed definitions and draws from Cattaneo and Chapman's (2010) three priorities for refining an empowerment theory, which include enhancing our understanding of empowerment as an iterative process, incorporating a range of analyses from individual to social levels of empowerment, and increasing our precision of definition. I strive to honor these priorities, using them to offer direction within an otherwise unruly maelstrom of theories, models, and applications.

**Power and control.** Concepts of power and control are central to the definition of empowerment. In the context of promoting wellness, I. Prilleltensky, Nelson, and Peirson (2001) defined power and control as "having the opportunity to (a) access valued material and psychological resources that satisfy basic human needs, (b) exercise participation and self-determination, and (c) experience competence and self-efficacy which instill a sense of stability and predictability in life" (p. 145). According to these authors, power and control derive both from internal capacities and external conditions and from a successful fit between individuals and their environments. I. Prilleltensky et al. (2001) conceptualized empowerment as an optimal location on a continuum of power and control, which extends from disempowerment to overpowerment. In other words, they contended that empowerment involves accessing enough power to satisfy personal needs and to advance collective goals in collaboration with others.

Some scholars and activists have asserted that power manifests in four distinct ways, as power-within, power-to, power-with, and power-over (e.g., Williams, Seed, & Mwau, 1994). Power-within refers to the internal strength that derives from self-acceptance, respect for self and others, self-esteem, self-awareness, confidence, and

assertiveness. It also involves developing one's critical consciousness of the power dynamics that operate in one's various environments—family, professional, sociopolitical environments—Freire's (1970) concept of conscientization. Power-to refers to our power to be and act in the world. It involves the power to develop knowledge and skills, to make decisions autonomously, to participate, and to transform unjust social structures and institutions. The *Oxfam gender training manual* (Williams et al., 1994) highlighted power-to as the essence of individual empowerment. Power-with represents a collective form of power, with which people feel empowered to organize and unite around a common purpose or understanding. Power-with privileges the good of the community. Finally, power-over involves relationships of control, such as domination, subordination, and intimidation, as well as the resistance to being controlled. I think that many of the problems related to power-over arise, in part, from the belief that quantities of power are fixed and that we need to struggle against one another to claim a share of the power (Sharp, 2010). Charlton (1998) may have alluded to a fixed-power perspective when writing about disability oppression and empowerment: "empowerment must translate into a process of creating or acquiring power. When power is taken, it is taken from someone. Someone loses" (pp. 122-123). Although I agree that the people and especially the institutions that are over-powered need to relinquish some power, I have little patience for metaphors of "winning and losing" (Charlton, 1998, p. 123).

I personally do not believe that the experience of empowerment is finite or that power is a scarce commodity. I aspire to live in a world where we can socially produce enough power for all people to meet their individual needs and to advance collective goals. I have based my dissertation on this aspirational image and on my hope/belief that

the scarcity mindset regarding power and empowerment is a fear-based mistake. I agree with Hur (2006) that, when a person's empowerment conflicts with collective empowerment, it is because "Empowerment is not effectively operating" (p. 530).

**Processes and outcomes.** One of the reasons that empowerment lacks a precise definition is that empowerment and by extension, disempowerment, involve both processes and outcomes (Hur, 2006; Perkins & Zimmerman, 1995). Neither the processes nor the outcomes are unidirectional or simple: they are complex changes involving people's power over material and social resources and power to make decisions in their lives (Datta & Kornberg, 2002). Cattaneo and Chapman (2010) and McWhirter (1994) emphasized the ongoing and iterative nature of the empowerment process, averring that an arrival at a fixed, empowered state does not exist. Even so, governments and nongovernmental organizations (NGOs) need to articulate measurable goals and empowerment outcomes so that they can evaluate how well they are creating environments in which historically oppressed or disenfranchised people can access material and social resources. Thus, outcomes as sojourns, if not arrivals, must also be an important part of a definition.

Hur (2006) considered empowerment to be a process because "It is fluid, often unpredictable, and changeable over time and place" (p. 524) and identified five stages in the empowerment process. Hur employed a method of theoretical synthesis by reviewing, comparing, and combining the research literatures from community psychology, education and women's studies, health studies, management, political science, and social work/social welfare. According to Hur, the path to empowerment included the existence of social disturbances, conscientization, mobilization, maximization, and the creation of a



new social order. In other words, empowerment begins with a sense of powerlessness in the face of social disturbances, such as “disadvantages, oppression, alienation, and stratification” (p. 529). Next individuals or groups start to raise their critical consciousness, becoming aware of how social and political structures relate to their experiences of powerlessness and of how they might go about changing power dynamics within themselves and in relation to their environments. Third, individuals and groups join with others to organize and mobilize collective action and to address social injustices. Fourth, empowerment grows or maximizes when power is shared with an increasing number of people. The final stage involves transforming unjust social systems and effecting a more just social order. Even though this path to empowerment involves stages, Hur conceptualized the empowerment process as nonlinear and dynamic.

Cattaneo and Chapman (2010) also proposed a model of the empowerment process. They based the six elements of their model on the concepts they identified as most important in the PsycInfo research literature, on the ease with which the concepts could be communicated, and on the applicability of the concepts in specific situations. In short, they defined the empowerment process as including personally meaningful and power-oriented goals, self-efficacy, knowledge, competence, action, and impact.

Personally meaningful, power-oriented goals are goals that are compatible with one’s sense of self and core beliefs and that aim to increase one’s social influence at any level of analysis. Self-efficacy is one’s perceptions and beliefs about one’s ability to organize and execute the skills needed to attain a certain level of performance (Bandura, 1986). Consistent with Freire’s (1970) concept of conscientization, Cattaneo and Chapman (2010) defined knowledge as “An understanding of the relevant social context, including

the power dynamics at play, the possible routes to goal attainment, the resources needed, and ways to obtain them” (p. 653). Competence pertains to one’s level of actual skill. Actions are any behaviors that are directed toward personally meaningful and power-oriented goals, motivated by self-efficacy, informed by knowledge, and executed with competence. Finally, impact refers to one’s perception of the effects of one’s actions on the environment. Cattaneo and Chapman concluded by encouraging researchers and practitioners (a) to think of the empowerment process model as iterative and as involving concepts that influence one another and (b) to consider access to resources, cultural values, and perceived stigma as possible mediators and moderators.

In addition to conceptualizing empowerment as a process, Hur (2006) described empowerment as involving outcomes because empowerment “can be measured against expected accomplishments” (p. 524) and identified four cognitive components (potential measurable outcomes) of individual empowerment. According to the same theoretical synthesis that highlighted a path to empowerment, Hur recognized meaning, competence, self-determination, and impact as components of individual empowerment. Meaning is the fit between the needs of one’s various life roles and one’s values, beliefs, and behaviors. Competence is the belief that one has the skills and abilities necessary to perform a job or task well. Self-determination, in this case, is the belief that one has personal control and freedom to make decisions and to initiate actions. Impact is the belief that one can make a difference in influencing the approaches, methods, or practices of a given organization or social system.

Hur’s (2006) theoretical synthesis also revealed four cognitive components of collective empowerment—collective belonging, community involvement, control over

organization in the community, and community building. Collective belonging is one's perception of being a part of a social network of peers—retaining a sense of autonomy while experiencing solidarity. Community involvement means participating in community activities or events that could affect power structures. Control over organization in the community entails gathering and directing forces to influence various organizations in one's community. Community building refers to creating a sense of belonging and cohesion throughout one's community that, in turn, increases people's collective abilities to work together, solve problems, make group decisions, and effect social change. In conclusion, Hur encouraged researchers and practitioners to consider the components of individual and collective empowerment at every stage of the empowerment process.

**Individual, collective, and contextual empowerment.** The multiple levels of analysis in relation to empowerment also detract from the facility with which people have been able to share a clear and succinct definition. Consistent with Bronfenbrenner's (1989) ecological model of human development, individual, collective, and contextual elements of empowerment are all multidimensional and interrelated (Zimmerman, 2000). In general, individual empowerment “relates to the way people think about themselves, as well as the knowledge, capacities, skills, and mastery they actually possess” (Hur, 2006, p. 530). Collective empowerment involves many sublevels, such as organizational or community empowerment, and involves the “processes by which individuals join together to break their solitude and silence, help one another, learn together, and develop skills for collective action” (Hur, 2006, p. 530). The ecological contexts of individuals and collectives are important because “empowerment is inherently locally located and

therefore is unlikely to be easily transferable to other locations and contexts” (Sharp, 2010, p. 10). Moreover, empowerment theory “suggests that actions, activities, or *structures* may be empowering” (Zimmerman, 2000, p. 46, emphasis mine). As with their definitions of empowerment, researchers and practitioners have articulated many different lenses within and around the individual, collective, and contextual distinction to help them analyze empowerment processes and outcomes.

On an individual level of analysis, Zimmerman (1995, 2000) offered the open-ended construct of psychological empowerment as a phenomenon relevant to all levels of empowerment analysis. It is an open-ended construct because the form it takes is dependent on the person, context, and developmental moment in the person’s life. In general, however, Zimmerman (1995, 2000) defined psychological empowerment as involving three interrelated dimensions: intrapersonal, interactional, and behavioral dimensions. The intrapersonal dimension involves the personality, cognitive, and motivational aspects of perceived control in a given domain (e.g., locus of control, self-efficacy, or perceived competence). The interactional dimension includes critical consciousness and the skills to exert influence in a given domain (e.g., to make decisions, solve problems, mobilize resources, or interact effectively with others). The behavioral dimension refers to the participatory or change-oriented actions that a person takes to exert some measure of control in a given domain. Zimmerman’s (1995) construct of psychological empowerment demonstrates how, even on the individual level of analysis, empowerment is a dynamic process with a variety of manifestations that are inextricable from interpersonal relationships and context.

Organizational empowerment is one example of collective empowerment under investigation (e.g., Peterson & Zimmerman, 2004; Zimmerman, 2000). Zimmerman (2000) divided the studies of organizational empowerment into research on empowering organizations and research on empowered organizations. An empowering organization is one that provides opportunities for individual members to gain power and control within the organization, and thus researchers can study empowering organizations by assessing the individual empowerment of its members—e.g., via Zimmerman’s (1995) construct of psychological empowerment. An empowered organization is one that has an influence on one or more systems in its social ecology (Zimmerman, 2000). To address empowered organizations, Peterson and Zimmerman (2004) proposed a conceptual framework involving dimensions of intraorganizational, interorganizational, and extraorganizational components. According to Peterson and Zimmerman, intraorganizational components refer to the characteristics of an organization’s internal structure and functioning that facilitate goal-directed behaviors in its members. Interorganizational components include the connections and collaborations among organizations. Extraorganizational components involve the actions of an organization or coalition of organizations to affect or shape the environment (e.g., disseminating information, delivering effective services, or bringing about policy change). Researchers can define and study the processes and outcomes of organizational empowerment along each of these three, interrelated dimensions.

Prilleltensky et al. (2001) discussed empowerment from a contextual perspective that integrated multiple systems of the social ecology. These authors argued that power and control are synonymous with opportunities. They discussed the importance of opportunities in family, community, and other environments that facilitated the

acquisition and development of material and psychological resources and the experience of social participation, self-determination, competence, and self-efficacy. They offered some examples, which included access to adequate family incomes, to meaningful work, to education, and to affordable and desirable housing. These examples of opportunities—and by extension, of power and control—depend on social policies to ensure that families with children have access to resources that promote wellness.

**A precise definition of empowerment?** A goal of my dissertation was to invite the Deaf and disabled women whom I interviewed to co-author a definition of empowerment by describing their empowerment journeys and experiences (processes and outcomes). Might their personal stories—viewed through the lenses of complex embodiment, the ecological model, and intersectionality theory—help give rise to possible models and metaphors of empowerment and identity? In turn, could such models offer increased precision to a definition of empowerment as it pertains to a multicultural sample of Deaf and disabled women activists from the Global South?

Prior to beginning the current exploration, however, I enunciated a broad, open-ended definition of empowerment. I conceptualized empowerment as the process of developing power-within, power-to, and power-with, while articulating or minimizing the presence of power-over. As part of my adherence to the ecological model of human development (Bronfenbrenner, 1989), I remained open to individual, collective, and contextual levels of empowerment analysis. Finally, I imagined empowerment as an ongoing process with the potential for meaningful outcomes or milestone experiences. McWhirter's (1994) aspirational definition of empowerment was most consistent with my framework. Thus, I sought to explore how participants developed critical consciousness

(an aspect of power-within), acquired the skills to gain reasonable control in multiple contexts (power-within and power-to), exercised control without violating the rights of others (power-to while minimizing power-over), and encouraged the empowerment of others in their communities (power-with).

**The paradox of empowerment.** Thinking deeply about the complexities within individual and collective empowerment is important for people engaged in the design or delivery of policies and programs that seek to empower disadvantaged individuals and groups. Like Williams et al. (1994), May (1972) categorized types of power, separating collective power into power-with and power-for components (he labeled them integrative power and nutrient power respectively). This articulation of power-for is consistent with the many policies and programs that involve people from privileged social groups seeking to empower people from disprivileged social groups. Although May acknowledged that we can find a great deal of love in expressions of power-for and power-with, he also asserted that forms of helping that cast recipients in a passive role, overshadow their existing capabilities, or delay their acquisition of important skills eventually function to disempower them, regardless of the good intentions of helpers. Gruber and Trickett (1987) agreed that "there is a fundamental paradox in the idea of people empowering others because the very institutional structure that puts one group in a position to empower also works to undermine the act of empowerment" (p. 353). Other scholars have gone so far as to perceive the "empowerment agenda" as "a project which secretes an insidious form of power, subjugating and subjectifying its objects in the process of fabricating them as 'subjects'" (Kelsall & Mercer, 2003, p. 295).

I agree that power-for is essentially a well-intentioned aspect of power-over. Colonial, patriarchal, and custodial forces have played a prominent role in the histories of Deaf and disabled women from the Global South. I, therefore, sought to sharpen my critical awareness of these forces as they manifested in the life experiences and identity stories of the participants in the current study.

## **Identity**

Like empowerment, identity is a multilevel construct that involves networks of relationships within individuals, among individuals and groups, and between individuals and their environments. Tajfel (1981), for example, defined identity as a construct and a continuous process, both of which are influenced by many personal and social factors. Burke and Stets (2009) defined an identity as a set of meanings that describes who one is when one claims particular characteristics that constitute one's unique personhood (a person identity), occupies a particular role in society (a role identity), or has membership in a particular group (a social identity). According to identity theory (e.g., Burke & Stets, 2009), person, role, and social identities operate in the same ways insofar as they refer to or incorporate social expectations and standards, involve negotiations between individuals' ongoing, situational perceptions and the feedback they receive, and include a complex network of emotions and agentic behaviors. Scholars across the social sciences continue to debate the concept of identity within developmental, individual, interpersonal, and sociocultural frameworks; how stable or fluid it tends to be; the degree of personal agency involved; and the mechanisms and magnitude of situational and social influences.



A number of theories have arisen across disciplines (Brewer, 2001) to explain how identities emerge, are maintained, and change as individuals develop, relate to others, and interact with social systems. Within sociology, identity theory is based on structural symbolic interactionism and addresses the content of identity as it interacts with language, signs, and symbols and with a complex, organized society (e.g., Burke & Stets, 2009). Theorists using identity theory tend to emphasize role identities, the multiple identities that a person has, the differential salience of multiple identities, and their hierarchical arrangement in a person's self-concept (e.g., Burke & Stets, 2009). Within social psychology, social identity theory (Tajfel, 1981) focuses particularly on explaining intergroup relations. Social identity theory emphasizes the emotions, cognitive processes, self-esteem, meanings, and social contexts involved in one's identities related to one's membership in various social groups (Tajfel, 1981). Identity process theory (e.g., Jaspal & Breakwell, 2014), also arising within social psychology, is a social constructivist perspective that draws from social representation theory and self-efficacy theory (Jaspal, 2014). It integrates multiple levels of analysis—intrapsychic, interpersonal, and social—and provides a holistic model of (a) the structure, content, and values involved in identity; (b) the centrality and salience of identity components; (c) the interaction of social and psychological factors in the production of identity content; and (d) the relationship between identity and social action (Jaspal, 2014). Finally, environmental psychologists have contributed place identity theory to the literature to accentuate the important role of built and other physical environments in shaping one's identity development (Dixon, Durrheim, & Di Masso, 2014; Hauge, 2007). Each of the theories noted above includes aspects relevant to the current study—e.g., multiple levels

of analysis, considerations of language and social constructions, awareness of multiple dimensions and different degrees of identity salience, attention to group identities and intergroup processes, a focus on how identity relates to social action, and the emphasis of place in shaping one's identity.

Much of the theoretical work on identity is beyond the scope of this literature review, and thus I do not go into further detail here. In the remainder of the current chapter, I review some concepts and ideas pertinent to a consideration of identity salience among Deaf or disabled women activists. Specifically, I focus on (a) social identities; (b) disability and Deaf identities; (c) models of disability and Deafhood; (d) identity development models; and (e) multiplicity, intersectionality, and identity salience.

**Social identities.** Consistent with the ecological model of human development (Bronfenbrenner, 1989), identity researchers have recognized that no self can exist without a context (e.g., Lachmann, 2004) or without attachment to important others (e.g., Ainsworth & Bowlby, 1991). Social identity, a focus of the current study, links the psychology/self-concept of the individual and the structures and processes of social groups within an individual's social ecology (Brewer, 2001). Tajfel (1981) defined social identity as "that part of an individual's self-concept which derives from his knowledge of his membership in a social group (or groups) together with the value and emotional significance attached to that group membership" (p. 255). Currently, no single shared definition of social identity exists because disciplines—ranging from psychoanalytic theory to sociology—have conceptualized and operationalized social identity in numerous and diverging ways (Brewer, 2001; Jackson & Smith, 1999). Brewer (2001) articulated and explained four variations on the theme of social identity to capture most

of the usages in the social science literatures: person-based, relational, group-based, and collective social identities.

According to Brewer (2001), person-based social identities are located in the individual and refer to aspects of the self that have been particularly influenced by membership in specific social groups or categories and by the shared socialization experiences that such membership entails. They include the aspects of one's person identity or individual self-concept that pertain to who one is as a member of a particular social group. Person-based social identities are often studied developmentally as in the identity development models reviewed later in this chapter.

Relational social identity (Brewer, 2001) includes identifications of the self in role relationships that transpire within larger group contexts. In other words, relational social identity includes the concept of role identity as perceived through the lenses of interpersonal relationships and social contexts. Such roles may be occupational, familial, or personal in nature—e.g., professor in relation to student, parent in relation to child, or friend in relation to friend—and transpire in the contexts of ecological systems, such as universities, families, or peer groups.

Group-based social identity (Brewer, 2001) refers to the perception of self as an integral or interchangeable part of a larger group. It is essentially the inverse of person-based social identities because the part-whole relation is reversed; it represents a movement away from perceiving the self as I and toward perceiving the self as part of we—for example, we as students/researchers/activists. When a group identity is engaged, individuals (a) expand their notions of self to include other group members and the experiences of the group as a whole and (b) and adapt their attitudes and behaviors so as

to assimilate better into the group and enhance group uniformity and cohesion. Group-based social identities also arise in some of the identity development models mentioned below.

Brewer (2001) explained that the term collective identity arises in the sociological literature on social movements and refers to the process by which group-self identifications take shape. Like group-based social identities, collective identities involve shared representations of the group based on common experiences, but the perspective shifts from an individual's perception of the group to the group's collective perceptions. In addition, collective identities refer to an active process of creating and shaping an image of what the group represents and of how the group as an entity would like others to perceive it. For example, a collective identity of the blind community in the United States would reflect how that community defined itself as a whole rather than how individuals in the community defined the group. Brewer pointed out that "The concept of collective identity provides a critical link between social identity (at both individual and group levels) and collective action in the political arena" and therefore, is important to the study of "identity politics" (p. 119).

**Disability and Deaf identities.** Age, gender, ethnicity, nationality, race, religion, socioeconomic class, and sexual/affectional orientations are some examples of social identities; so too are Deafhood and disability. Like many other social identities, Deaf and disability identities involve components of social categorization and meaning making, as well as physical and biological components (Forber-Pratt, Lyew, Mueller, & Samples, 2017). Disability scholars and activists have, however, struggled to secure the acceptance of disability in conversations about valued social identities. Perhaps the difficulty arises,

in part, because the embodiment of disabled people is so diverse and because majority cultures and other activist groups perceive impaired bodies or brains rather than disability, a construct whose definition includes sociopolitical conditions in addition to features of people's body-minds (e.g., Taylor, 2004). Or perhaps disability is left out of conversations about identity because claims about disability have historically been used by people in power to oppress other disenfranchised groups; for example, arguments denying suffrage to women, black Americans, and various immigrant groups in the United States cited the supposed disabilities these groups possessed (Baynton, 2017; Garland-Thomson, 2017; Longmore & Umansky, 2001). Siebers (2008) suggested that "the presence of disability further feminizes the female other, further racializes the racial other, and further alienates the alien other" (p. 180). Siebers's observation is just one example of the complex ways that social/cultural identities can intersect, interact, and shape each other.

Disability identity, like other concepts in this dissertation, does not involve a widely-accepted definition. Research on the nature and development of disability identities is limited. Moreover, people's experiences and identities of disability may differ widely based on whether they were born with or acquired their disabilities, how chronic or temporary their disabilities are, to what extent their disabilities are apparent to others, the degree of dissonance between their appearance/functioning and their environments, and the presence of other identities—as tends to be the case with any social identity. Dunn and Burcaw (2013) defined disability identity as involving "a positive sense of self, feelings of connection to, or solidarity with, the disability community (para. 1). Forber-Pratt et al. (2017) offered a broader definition: "disability

identity can be considered a unique phenomenon that shapes persons' ways of seeing themselves, their bodies, and their way of interacting with the world” (p. 198).

Potentially relevant to the Deaf and disabled activists in the current study, Putnam (2005) proposed a framework for conceptualizing political disability identity, “the attitudes and beliefs that psychologically link people with disabilities to one another for the purpose of political activism” (p. 188). Putnam’s review of the empirical literature yielded an outline of six domains that structured political disability identity: self-worth, pride, discrimination, common cause, policy alternatives, and engagement in political action. Self-worth referred to one’s beliefs that disabled people, including one’s self, are of the same worth as nondisabled people and that, although disabled people are socially undervalued, they can be productive contributors to society. Pride involved claiming one’s disability, considering one’s disability to be part of the human condition, believing that body-mind limitations are not inherently negative but can become so in certain cultural, social, and physical environments, and recognizing that one belongs to a cultural minority group. Discrimination referred to one’s understanding that disabled people are negatively stereotyped, that disabled people are typically treated differently from and often worse than nondisabled people, and that such discrimination results in inequality of opportunity and access to social and economic resources. Common cause included one’s beliefs that persons with disabilities share similar experiences, that some of these experiences should be changed, that the contributing factors to these changeable experiences are similar to one another, and that advocating for changes as a group requires developing a common political agenda. The policy alternatives domain involved one’s beliefs that disability is not characteristic of individuals, that achieving disability

rights requires both modifying environments and enhancing individual capacities, and that public policy has a major influence on experiences of disability. The final domain of political disability identity, engagement in political action, included one's beliefs that disabled people are a political constituency group, that disability constituency groups represent political minority groups, and that engagement in political action by and for these constituency groups can affect policy change.

Research within Deaf studies has also explored Deaf identities. De Clerck (2016) defined Deaf identity as “a complex process learned by interacting with changing cultural contexts and practices in the multiple communities in which deaf people participate” (p. 11). In a study of 267 Deaf participants in the United States, Bat-Chava (2000) found evidence of four general clusters of deaf identities: culturally hearing, culturally Deaf, bicultural, and negative or culturally marginal identities. Participants with culturally hearing identities perceived deafness as a disability, believed that clear speech was more important than signing well, did not feel at all part of the Deaf community, and held more negative attitudes toward Deaf people. People with culturally Deaf identities perceived Deafhood as a culture, considered signing to be more important than oral speech, felt very much like a part of the Deaf community, and held attitudes toward other Deaf people that were neither positive nor negative. People with bicultural identities had experiences in both Deaf and hearing communities, felt that both sign language and speech were important, indicated that their identification with other Deaf people was of average strength, and held the most positive attitudes toward Deaf people as compared to other participants in the study. Finally, a small group of people described holding negative or marginal identities, which involved feeling ambivalent about their

deafness/Deafhood, believing that both sign language and speech were extremely important, reporting low levels of group identity and connectedness, and describing below-average levels of positive attitudes toward Deaf people.

Deaf cultures, or the “beliefs, mores, artistic expressions, behaviors, understanding, and language expressions that Deaf people use” (Leigh, Andrews, & Harris, 2018, pp. 7-8), exist all across the world. Some people argue that Deaf people constitute an ethnic group (e.g., Golberg, 2011) because they share a collective name (Deaf), a sign language (e.g., ASL), feelings of community, behavior norms, distinct values, culture knowledge and customs, social/organization structures, histories, arts, and kinship or sense of human connection (Leigh et al., 2018). Deaf cultures consist of a rich array of arts including visual and tactile arts, such as drawings, paintings, ceramics, or sculptures; performing arts, such as theater, dance, storytelling, comedy, and music; literature, such as written and sign poetry, novels, and short stories; media arts, such as print and sign media, photography, cinematography, and digital arts; graphic design; fashion design; and culinary arts (Golberg, 2011; Leigh et al., 2018). Deaf View/Image Art or De’VIA refers to art created by Deaf artists that specifically expresses cultural Deaf experiences (Leigh, et al., 2018). De’VIA can take the form of resistance art, which might express themes of audism, oralism, identity confusion, or eugenics, or affirmative art, which might express themes of empowerment, sign language, self-acceptance, or Deafhood (Leigh et al., 2018).

Bauman and Murray (2017) offered the term Deaf-gain, which refers to the many benefits of being Deaf. They detailed some areas in which the unique stance of Deaf people can make important cognitive, creative, and cultural contributions to benefit all



humanity. Such contributions include (a) the insights that sign language studies offer about language acquisition and structure, visuospatial processing, and visual learning; (b) the ways in which the visual, spatial, and kinetic dimensions of sign languages might advance the precision and rhetorical power of academic discourse; (c) the potential of Deaf innovations in film, architecture, and community planning; (d) the new literary forms emerging from sign poetry; (e) the transnational perspectives and communications that International Sign allows; and (f) the examples of collectivity that Deaf cultures offer the world.

**Models of disability and Deafhood.** Understanding the ways in which people have conceptualized deafness/Deafhood and disability can be helpful when considering identity. These understandings have evolved from individualist, deficit-based models to models focused on physical and social environments to models of complex interactions between individuals' body-minds and multiple social systems. People's Deaf or disability identities can reflect one or more of these models across situations and contexts (Forber-Pratt et al., 2017; McIlroy & Storbeck, 2011).

The moral model considers disability, including deafness as a hearing deficiency, to be a personal tragedy, curse, or sign of spiritual deficit within one's self or one's family (Dunn & Andrews, 2015; Goodley, 2017; Olkin, 1999). This conceptual model, with a few tendrils reaching back to ancient Greece and Rome, flourished within Judeo-Christian religious teachings and texts and subsequently pervaded literature, art, and all forms of media with Deaf and disability stereotypes, metaphors, and moral judgements (Baynton, 2006; Davis, 2017; Oliver & Barnes, 2012). Within the moral model, people might use derogatory terms like "moron" or "cripple" to refer to other people whom they

view as inferior due to their disabilities (Dunn & Andrews, 2015, p. 258). Historically, in the United States, the moral imperatives of nationalism and a desire to rescue Deaf children from their alien-ness played important roles in the practice of oralism, which refers to the opposition to sign languages and the exclusive use of lipreading and speech in the education of Deaf children (Baynton, 2006; Public Broadcasting System, 2007). Today, the moral model plays an implicit role in hot button topics such as cochlear implant surgery on Deaf children, institutionalization, assisted suicide, euthanasia, involuntary sterilization, genetic counseling, and selective abortions, in which the morality of allowing people to disseminate or live with deafness or disabilities is often under debate (Hubbard, 2006; Lane, 2006; Olkin, 1999; Saxton, 2017).

The medical model represents disability as a deficit of one or more bodily systems or structures—as a hearing impairment in the case of deafness and mental disorders in the case of psychosocial disability (Dunn & Andrews, 2015; Goodley, 2017; McIlroy & Storbeck, 2011; Olkin, 1999; Peterson & Elliott, 2008; Peterson, Mpofu, & Oakland, 2010; Smart & Smart, 2006). According to the World Health Organization (2001), the goals of the medical model involve diagnosing, treating, and curing disease, disorder, or injury; disability can fall under any or all of these categories. Traditionally, language used within the medical model has involved referring to people solely according to their supposed impairments—for example, “the retarded,” “deaf-mutes,” “spastics,” or “the feeble-minded” (Dunn & Andrews, 2015, p. 258). Some scholars in the British disability movement (e.g., Shakespeare, 2017), have traced person-first language, which they view as euphemistic, back to the medical model and its tendency to reduce the complex problems of disabled people to issues of medical prevention, cure, or rehabilitation.

Although the traditional medical model and its present-day iterations, such as the rehabilitation model (Dunn & Andrews, 2015), have greatly humanized responses to disability, they can continue to frame disability as a deficit, to perpetuate paternalism/custodialism, and to accentuate a power differential between people with and without disabilities.

The moral and medical models both situate disability firmly in the individual and perpetuate a charity ethic across the world (Charlton, 1998; Goodley, 2017; Oliver & Barnes, 2012). Just as people sometimes fail to recognize the paradox of empowerment as they seek to empower others (Gruber & Trickett, 1987; Kelsall & Mercer, 2003; May, 1972; McWhirter, 1994), hearing and nondisabled people seldom perceive the paternalistic and colonizing shadow that disability charities cast. Religious and medical charities often frame deafness and disability as personal tragedies, portray Deaf and disabled people as pitiable, assume that these people need help, and justify controlling them without consulting them directly (Charlton, 1998; Goodley, 2017; Lane, 2006). Goodley (2017) referred to these practices as “person-fixing” (p. 9), and Charlton (1998) explained how charities function as agencies of control: “Charities, at best, create dependency; at worst, they further degrade and isolate” (p. 93). In reflecting on the intersection of colonialism and disability in the Global South, Grech (2015) wrote,

The empire dominated, disabled (including through the diseases it imported), then brought in charity and medicalisation not only to 'heal' and correct but above all to learn about itself and develop its practices (medical as well as those of domination), by experimenting on the body of the colonised. (p. 12)

In response to the moral and medical models, the social model shifted the focus away from individual deficits and onto the social oppression, cultural discourse, and environmental barriers encountered by people with disabilities and people who are Deaf

(Dunn & Andrews, 2015; Goodley, 2017; Peterson & Elliott, 2008; Peterson et al., 2010; Shakespeare, 2017). Within a strong version of the social model, disability is understood as a social construction and cultural creation: if physical, technological, and social environments were fully accessible and if social inequities, prejudice, and discrimination did not exist, then disabilities would not exist (Olkin & Pledger, 2003; Putnam, 2005). Thus, the goals of the social model involve eliminating barriers, passing antidiscrimination legislation, and following the lead of Deaf and disability communities in crafting other responses to social oppression (Dunn & Andrews, 2015; Olkin, 1999; Shakespeare, 2017). Some scholars in the United States have identified person-first language as arising from the social model as a means of preserving the humanity and individuality of people with disabilities rather than emphasizing body-mind impairments (Dunn & Andrews, 2015). By externalizing the disability, person-first language avoids the objectifying or essentializing language of the moral and medical models and resists the idea that people with disabilities are suffering or are victims without control over their lives (Dunn & Andrews, 2015). The social model, as it has progressed in Britain, has given rise to identity-first language (Goodley, 2017; Shakespeare, 2017), as has the minority model in the United States (Dunn & Andrews, 2015).

The minority model (Dunn & Andrews, 2015; Goodley, 2017; Olkin, 1999; Putnam, 2005), sometimes called the sociopolitical model (Smart & Smart, 2006), is an iteration of the social model active in North America and based on American ethics of individuality and achievement (Goodley, 2017; Shakespeare, 2017). Proponents of the minority model sought to return an emphasis to individual features of Deafhood and disability, this time as positive human attributes rather than as moral or medical deficits

(Dunn & Andrews, 2015; Lane, 2006; McIlroy & Storbeck, 2011; Olkin & Pledger, 2003). North American scholars and activists working within the minority model assert that disability is a distinct cultural identity and sociopolitical experience that involves a large and diverse population and believe that, just like other cultural experiences, disability can be a valued and celebrated part of one's identity (Dunn & Andrews, 2015). Similarly, in the case of Deafhood, advocates of this sociopolitical model recognize Deaf people as members of a sociolinguistic minority group and concentrate on Deaf rights (McIlroy & Storbeck, 2011). In the United States and Canada, identity-first language grew out of the minority model as an expression of pride and as a counter-response to the historical oppression and marginalization of Deaf and disabled people (Dunn & Andrews, 2015). Goals of the minority model, like the goals of models that focus on other oppressed groups, involve articulating and addressing power differentials, resisting oppressive narratives and structures, celebrating Deaf and disability identities and culture, and building community (Dunn & Andrews, 2015; O. Prilleltensky, 2009). Critical Deaf and disability studies scholars, some of whom operate within a minority model, draw from, integrate, and add to feminist theories, racial and ethnic studies, and queer theories and utilize an intersectionality framework. In the words of Clare (1999), "gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race . . . everything finally piling into a single human body" (p. 123).

More recently, concepts of disability and Deafhood have sought to retain the empowering and cultural aspects of sociopolitical models while better integrating the complex and embodied experiences of individual Deaf and disabled people. For example,

professionals in medicine, rehabilitation, and mental health (e.g., Peterson & Elliott, 2008; Peterson et al., 2010) have articulated a biopsychosocial model of disability, which considers interactions among body structures and functions, human activity, social participation, environmental factors, and personal factors that include multiple identities. A goal of the biopsychosocial model is to integrate the subjective, functional, and environmental components of disability into standard medical definitions, such as the definitions that appear in the *International classification of functioning, disability, and health* (ICF; World Health Organization, 2001). Some disability scholars have criticized the WHO and the biopsychosocial model of the ICF for universalizing highly industrialized, Anglo-Nordic/North American perspectives to the rest of the world, thus ignoring the culturally-specific conditions that create disability (Goodley, 2017; Grech, 2015; Oliver & Barnes, 2012; Titchkosky & Aubrecht, 2015).

Other interactionist models that consider material bodies and worlds alongside culture and social representations have arisen within disability studies. Siebers (2008), for example, offered the disability theory of complex embodiment (defined in Chapter I). Garland-Thomson (2011) illustrated and elaborated Siebers's (2008) theory of complex embodiment by offering the concept of misfit or a "discrepancy between body and world, between that which is expected and that which is" (p. 593). Misfit can refer simultaneously to the Deaf, disabled, or neuroatypical person who does not fit into an unsustainable environment, as well as to the act of not fitting (Garland-Thomson, 2011). Some advantages of discussing disability in terms of misfit are that the discussions (a) attend well to physical spaces, histories, and other social ecological contexts; (b) emphasize dynamic relationships between specific body-minds, rather than a general

disabled body, and their various environments; (c) consider both the material and the socially constructed; and (d) recognize the real consequences of injustice and discrimination.

Deaf studies researchers in South Africa, McIlroy and Storbeck (2011), proposed a bicultural or dialog model to sharpen focuses on interactions between individual bodies and social/cultural features of identity. With this model they theorized how the world is experienced by Deaf people in a way that integrates aspects of the medical and social models and transcends the medical/social binary. McIlroy and Storbeck offered the term/spelling of “DeaF” to represent the diverse and bicultural identities of DeaF people who navigate Deaf and hearing worlds. The dialog model includes oral deaf, signing Deaf, and bicultural DeaF people. Adherents of the dialog model value the bodily experiences of deafness as well as the cultural and sociolinguistic minority experiences of Deafhood.

**Identity development.** Researchers and scholars have proposed a number of identity development models that, historically, traced stages of one dimension of social or cultural identity over time. For the purposes of this literature review, I offer a brief overview of models pertaining to cultural and leadership identity development. I particularly cite examples pertaining to woman, Deaf, and disability cultural identities—the identities of which participants claimed some form when they applied for the 2013 WILD program. Many of these identity development models have derived from Eurocentric worldviews (Myers et al., 1991) and have been proposed by researchers in the Global North. Thus, they may or may not be relevant to the participants in the current study, who hold a wide range of national and other cultural identities.

Cultural identity is “an umbrella concept for the many types of social identities (e.g., racial, ethnic, gender, or sexual) that comprise our sense of self as a member of a group within the multiple contexts in which we live” (Coleman, Norton, Miranda, & McCubbin, 2003, pp. 40-41). Cultural identity development models assume that embodied and constructed factors such as gender, social class, and race/ethnicity have meanings outside of the individual and that individuals must incorporate these meanings into their identities to achieve coherent senses of self (Coleman et al., 2003). Models of cultural identity development have addressed identities from cultural groups considered to be oppressed or in the minority, as well as identities from groups considered to be dominant or in the majority. In relation to racial and ethnic identity, Helms (2007) reminded us that these theories “are intended to describe group-specific development in particular sociopolitical contexts” (p. 236). Thus, I only touch briefly upon minority and majority identity development models to offer the reader a general sense of how such identities might develop in the context of the United States.

Models of minority or oppressed cultural identity development tend to follow a few general stages with the caveat that people may move through the stages in a nonlinear and iterative fashion. Although they recognized the differing terminology in the various models, Myers et al. (1991) articulated the general stage pattern as follows:

Individuals progressively experience (a) a denial, devaluation, or lack of awareness of their oppressed identity; (b) a questioning of their oppressed identity; (c) an immersion in the oppressed subculture; (d) a realization of the limitations of a devalued sense of self; and (e) an integration of the oppressed part of self into their whole self-identity. (p. 55)

I would add that many of the models also include an element of engaging in social action, especially in the later stages. Myers et al.’s description of a general progression holds



fairly well for models of feminist identity development (Downing & Roush, 1985), womanist identity development (e.g., Ossana, Helms, & Leonard, 1992), Deaf identity development (Glickman & Carey, 1993; Ohna, 2004), and disability identity development (Gill, 1997). Over time, theorists have come to emphasize the variations and fluidity of identity development by considering statuses (e.g., Forber-Pratt & Zape, 2017) or schemas (e.g., Carter, Helms, & Juby, 2004), instead of stages and by investigating profiles of people's endorsement of multiple statuses/schemas at the same moment in their identity development (e.g., Carter et al., 2004).

Theorists have also proposed identity development models pertaining to majority or dominant cultural identities. As an example, Helms's (e.g., 2017) white racial identity development model described distinct schemas—the cognitive, emotional, and behavioral processes that guided interpretations of racial information among white people in the United States. The different schemas arose in two unfolding phases: internalizing racism and subsequently abandoning racism. Internalizing racism involved schemas of (a) obliviousness or denial of the significance and differential meaning of race and of whiteness in particular; (b) conscious acknowledgement of whiteness and its associated privileges, an awareness that is in conflict with one's moral socialization; and (c) idealization of whiteness, of “right-thinking” white people, and of white culture in order to maintain systems of privilege and to assuage one's internal emotional turmoil (Helms, 2017, p. 719). Abandoning racism involved schemas of (a) perceiving one's self and one's culture as superior to people of color and locating race and racial tensions in people of color or in “bad” white people rather than in one's self; (b) acknowledging whiteness as a source of racism and examining one's own and other white people's roles in

perpetrating and maintaining it; and (c) committing to a lifelong process of discovering and defining oneself in positive and moral terms as a white person (p. 720). Although very few participants in the current study identified as racially white, I mention Helms's (e.g., 2017) model, first, as an example of majority identity development to consider when reflecting on participants' intersections of oppressed and privileged identities and second, as a model to help me frame my own processes as a white researcher from the United States.

Using specific cultural identity development models has advantages and disadvantages. The use of these models has helped researchers and practitioners go beyond thinking about broad between-group differences to investigate individual differences in internalized socialization processes and more complex cognitive, emotional, interpersonal, and behavioral dimensions (Coleman et al., 2003; Helms, 2007; Ponterotto, 2010). At the same time, focusing on a single aspect of social identity can fail to account for multiculturalism within society, the heterogeneity of identity development processes, and the effects of intersectionality (Coleman et al., 2003; Myers et al., 1991; Ponterotto, 2010; Sevig, Highlen, & Adams, 2000). Moreover, inconsistencies among researchers in operationalizing the relevant terms, in explaining their sampling practices, and in identifying effective and theoretically congruent methodologies have led to varying levels of success in establishing construct validity of the cultural identity development models (Coleman et al., 2003; Helms, 2007; Myers et al., 1991; Ponterotto, 2010).

Komives, Longerbeam, Owen, Mainella, and Osteen (2006) proposed a model of leadership identity development. This model has potential relevance to the activists who

participated in the current study, both in terms of their identities and their leadership or empowerment experiences. The model arose out of grounded theory research with college students in the United States and reflected a developmental process of how they situated themselves in relation to leadership over time.

The six stages of leadership identity development that emerged in Komives et al.'s (2006) model included awareness, exploration/engagement, leader-identified, leader-differentiated, generativity, and integration/synthesis. Awareness involved beginning to recognize leadership happening in the world, looking to role models and authority figures as examples, and depending on the affirmation of others as a source of motivation. Exploration/engagement involved seeking opportunities to explore one's various interests, learning from peers and authority figures, starting to build skills and self-confidence, and beginning to internalize the feedback that one has leadership potential. The leader-identified stage involved recognizing leader as a specific role or position of responsibility, perceiving one's self as independent when in a leadership role and dependent when in a membership role, narrowing one's interests and leadership focuses, identifying new skills to learn and new ways of relating to others, trying out different leadership styles, continuing to look to mentors and other peer leaders as examples, and engaging in reflective learning. The leadership-differentiated stage involved recognizing leadership as a process of shared responsibility and collaboration, committing to interdependence by building community within the group, committing to one's role as a group member, processing one's experiences more deeply with mentors and peers, raising one's awareness of diverse perspectives, gaining confidence, recognizing the existence of multiple systems, and perceiving leader as a characteristic rather than a

position. Generativity involved developing personal philosophies of leadership, focusing on sustainability of the group, committing to passions and purposes that transcended specific groups, serving as role models and mentors to emerging leaders, increasing self-reflection and openness to feedback from mentors and peers, and defining leadership as a process and as a responsibility of all group members to the group. Integration/synthesis involved having confidence in one's own effectiveness across contexts no matter one's official role, attending more carefully to different contexts, committing to life-long learning and development, reflecting on the connections between one's values and actions, recognizing the benefits of processing one's experiences with others, and perceiving not only the interdependence of group members but the interdependence of groups within larger systems.

Consistent with Bronfenbrenner's (1989) ecological model of development, researchers have argued that increasing attention to social ecological factors is particularly important in understanding identity and identity development (Coleman et al., 2003; Seaman, Sharp, & Coppens, 2017). Seaman et al. (2017) encouraged identity researchers to attend to developmental context (how environmental conditions constrain and allow individual-level processes) and developmental timing (both sequential changes across the life span (chronosystem) and the connections between earlier and later developmental achievements) in addition to their traditional focuses on the content of identity over time. Coleman et al. (2003) articulated the advantages of using an ecological perspective to understand social/cultural identity as allowing researchers to better explore (a) how one's internal identity concepts and other people's external perceptions of one's identity develop within complex and multilayered social contexts;

(b) how people make sense of their person-based, relational, group-based, and collective social identities and of the various ecological systems that situate their lives; and (c) how specific aspects of people's identities are the same and different across microsystems, mesosystems, exosystems, and macrosystems (Coleman et al., 2003). Seaman et al. believed that focusing simultaneously on content, developmental context, and developmental timing could aid identity researchers in evaluating the contributions of different theoretical and research traditions, in illuminating the tensions that exist across traditions, and in establishing guidelines for integrating identity theory.

**Multiplicity, intersectionality, and identity salience.** The interrelated concepts of multiplicity, intersectionality, and identity salience are important to any study of identity, power, and context. The notion that a person has multiple identities (Burke & Stets, 2009) or multiple elements of a single identity (Breakwell, 2014) permeates the literatures of both psychology and sociology (Deaux & Burke, 2010; Stirratt, Meyer, Ouellette, & Gara, 2008). Within counseling psychology, Hays (2008) defined multiplicity in terms of the individual and cultural influences on one's identity, including, for example, age and generational influences, disabilities acquired early and later in life, religion and spirituality, ethnic and racial identity, socioeconomic status, sexual identity, indigenous heritage, national origin, and gender. Intersectionality, a conceptual framework of the current study, goes beyond a simple recognition of the multiplicity of identities to include a careful consideration of multiple systems of oppression and how their interaction produces and reproduces social inequalities (Cole, 2008; Collins, 2000; Crenshaw, 1989, 1991; Hankivsky et al., 2010). Identity salience, an explicit focus of this research, refers to the elements of one's identity that, in relation to one's ecological

context, are especially significant on a psychological level (Yakushko, Davidson, & Williams, 2009).

More and more scholars are beginning to study identity and power in a manner that recognizes multiplicity and intersectionality. For example, researchers have developed a variety of models to sort through and study the operation of multiple identities and their differential salience in relation to context (e.g., Abes, Jones, & McEwen, 2007; Burke & Stets, 2009; Stirratt et al., 2008). Others have theorized within and intersectionality framework, offering important analyses of the material and social consequences of living at the intersections of multiple oppressions (e.g., Collins, 2000; Crenshaw, 1989, 1991; Erevelles & Minear, 2017; Friedner & Kusters, 2015; Grech & Soldatic, 2015; Hankivsky et al., 2011; McRuer, 2017; Mohanty, 2003; Schulz & Mollings, 2006; Siebers, 2008).

Research with Deaf and disabled women from the Global South involves using intersectional paradigms (Collins, 2000) that include, but are not limited to, feminisms, Deaf and disability studies, and postcolonial and Global South studies. Uneasy relationships and important conversations/coalitions exist across these disciplines. A comprehensive review—not to mention understanding—of these conversations and coalitions is beyond the scope of this literature review and of my ever-evolving scholarship. I seek, however, to introduce a few themes and important terms in the remainder of this section.

A number of scholars have advocated for improving the interactions among and integrations of feminisms and disability studies. Schriempf (2001), for example, believed that an interactionist bridge for feminism and disability could help scholars move away

from binaries, such as sex-gender or impairment-disability, and toward a simultaneous and multidirectional account of the material world and its cultural representations. Some scholars have noted this movement as important to the field of critical disability studies (e.g., Meekosha & Shuttleworth, 2017). Garland-Thomson (2017) discussed integrating disability and feminist theories specifically in relation to topics of representation, the body, identity, and activism. Specifically, Garland-Thomson (2017) encouraged feminist-disability scholars to explore (a) the ways that Western thought has long conflated representations of bodies perceived as female, as disabled, or as bodies of color and marked these bodies as expendable; (b) how these ostensibly deviant body-minds have been materially and politically disciplined and harmed through discourses of medicine and appearance; (c) the role of power relations in a feminist ethic of care and how human interdependence and universal need for assistance might advance conversations about rights and subjectivity; (d) the multiple, intersecting, and fluctuating embodied identities of disabled women and the amplified or conflicting stereotypes that they experience, for example, around sexuality and motherhood; and (e) how disability and feminist activism, which can include and infiltrate areas of fashion modeling and academic engagement with multiple, partial, and paradoxical theories and methodologies, can transform social landscapes and promote social justice. Meekosha and Shuttleworth (2017) added multiculturalism, cross-cultural dialogues, and socioeconomic analyses to the topics that Garland-Thomson (2017) discussed as important to feminist and disability studies. As I reviewed these topics that arose at the intersection of feminisms and disability studies, I began to anticipate that themes relating to body-minds; to structural, socioeconomic, and social barriers; to the medical establishment; to appearance; to issues of autonomy,

dependence, and interdependence; to sexuality; to motherhood; and to creative activism might arise—perhaps in paradoxical forms—in participants’ stories.

Critical disability studies and Deaf studies must also join and dialogue with post-colonial and Global South studies (Bauman & Murray, 2017; Goodley, 2017; Ladd, 2008; Meekosha & Shuttleworth, 2017). Grech and Soldatic (2015) explained how, thus far, post-colonial scholars have almost entirely overlooked disability when exploring themes of identity, representation, space, historicity, and neocolonial practices. Conversely, they explained that “the hegemonic global North disability studies” are disconnected “from the histories, contexts and cultures” in the Global South, a geopolitical space that arose from histories of “power and empire” (p. 2).

Within international and transnational Deaf studies, Kusters and Friedner (2015) advocated using the concept of “deaf-same,” or the “shared experience of being deaf” (p. x) in both affirmative and critical ways. They encouraged scholars and activists from the Global North to exercise care when using concepts of Deaf identity, Deaf culture, Deafhood, audism, and Deaf-gain, for example. Although many of these concepts have had affirming and empowering effects, they warned against emphasizing deaf-same to the exclusion of deaf difference, noted the existence of many manifestations of Deaf identity and culture, and urged researchers to situate such concepts in time and space. They believed that attending to power could also help researchers distinguish local, cultural, and national differences from issues of inequality

Although many themes are worth exploring within the collaborations among Deaf, critical disability, and post-colonial studies, I wish to touch upon critiques of the WHO and the UN’s CRPD, organizations that factored prominently in the beginning of



this chapter. Titchkosky and Aubrecht (2015), for instance, contended that the WHO reflects a history of colonialism and operates as a colonizing force today. They elaborated the example of the WHO's Mental Health Improvements for Nations Development (MIND) project, and argued that the MIND project presents a framework of mental health crisis, describes people with psychosocial disabilities as representing an economic/productivity burden, and promotes intervention within a Western scientific medical paradigm. Essentially, Titchkosky and Aubrecht argued, the WHO claims that failing to invest in mental health is costly to a country's productivity and development and that a rational investment in mental health involves accessing definitions, research, technologies, and treatments that are designed, managed, and patented by Western powers. Similarly, Meekosha and Soldatic (2011) outlined how Northern discourses of human and disability rights strongly influenced the UN's CRPD (Meekosha & Soldatic, 2011). They argued that the CRPD's adoption of a social over medical model of disability—though helpful in identifying barriers related to social attitudes and state policies—ignores the ways that invasion, colonization, and globalization are root causes of major human rights violations, wars, poverty, famine/malnutrition, and the ecological degradation of land across the Global South, all of which have a harmful impact on people's body-minds. On an even more basic level, Stein (2015) pointed out that the CRPD has very few specific directives that could guide ratifying states in implementing the CRPD and that the very barriers that the CRPD is meant to address can impede local activists from engaging effectively with legal/political processes. Meekosha and Soldatic believed that, by better supporting and attending to disability activism coming out of local spaces across the Global South, transnational disability rights advocates could help

shift the disability rights discourse to better attend to global power imbalances; address poverty and redistributive justice; cast disabled people as agents rather than as victims of rights violations; encourage global development institutions to consider disabled children and adults; include people who acquire deafness or disabilities due to injury, illness, or trauma in the definitions of disability; recognize empowering aspects of medicine; honor disabled people's own indigenous, culturally-based, or context-dependent interpretations of disability and of their needs; and incorporate understandings of emancipation that are more relevant to specific cultures and contexts.

## **Conclusion**

Deaf and disabled women activists from the Global South can share multiple salient identities and social locations, differ significantly in others, assign similar and different meanings and degrees of salience to their identities, and demonstrate different degrees and types of empowerment. Their salient identities develop within contexts of connected systems and structures of power—state and local laws and policies, economic structures, educational and religious institutions, media practices, and cultural beliefs—that again involve many similarities and differences. Their experiences can showcase interlocking sources of oppression, as well as sources of privilege, and thus their unique and shared empowerment experiences unfold against a complicated backdrop of multiplicity, intersectionality, and ecology.

Surveying literatures of empowerment, intersectionality, and identity salience in a manner that honors the ecological embeddedness of these concepts is necessarily a sprawling, complex process. Many fundamental constructs, such as the nature and types of empowerment—e.g., individual, collective, and contextual (Hur, 2006; I. Prilleltensky

et al. 2001)—and of social identity—e.g., person-based, relational, group-based, and collective (Brewer, 2001), are still under debate. Moreover, the multiple dimensions and contextual manifestations of these constructs render the topic difficult to organize, let alone quantify for the purposes of research or program evaluation.

Empowerment is, nevertheless, explicitly named in a number of international goals for the promotion of gender equality and Deaf/disability rights, and thus the processes and manifestations of empowerment are deserving of increased scholarly attention. Governments and NGOs all over the world have declared intentions to advance the empowerment of people whose rights are not widely recognized or realized. The social, political, economic, physical, and psychoemotional wellbeing of many people depends on their potential to develop empowerment (e.g., Friis-Hansen & Duveskog, 2012; I. Prilleltensky et al., 2001).

Identity processes and outcomes appear to relate to various aspects of wellbeing and social action, including empowerment. Researchers have investigated the links between identity and perceptions of health and wellness (Lee & Sum, 2011), psychological wellbeing (Caldwell, Guthrie, & Jackson, 2006), psychological empowerment (Molix & Benthencourt, 2010), self-esteem (Ossana et al., 1992), locus of control and self-efficacy (Letlaka-Rennert, Luswazi, Helms, & Zea, 1997), learning processes and empowerment (De Clerck, 2016), and leadership (Sanchez-Hucles & Davis, 2010), to name a few examples. Thus identity and empowerment appear to relate to one another within a complex network of wellness and social actions. Moreover, intersectionality theory knits together concepts of identity, social location, and power (Cole, 2008, 2009; Crenshaw, 1989, 1991; Hankivsky, et al., 2011; Schulz & Mollings,

2006), which recommends these concepts as particularly well-suited to study in concert with one another.

I intend the current dissertation to add to the existing literature by investigating the interwoven layers and strands of identity, empowerment, and social ecology in the stories of 21 Deaf and disabled women activists from across the world. By using conceptual frameworks of ecological, intersectionality, and complex embodiment theories (described in Chapter I) and constructivist grounded theory analyses (described in Chapter III), I had an opportunity to practice the kind of conceptual and analytic complexity that I believe necessary to the study of human experience. With these frameworks and research methods, I hoped to sketch some models and metaphors related to intersecting identities and empowerment. The most profound contribution of the current study, however, is the participants' stories themselves. These stories demonstrate the wondrous intricacies of identity and empowerment more effectively than any analyses that I could offer, and I am grateful to set the stage and provide a platform for the stories that participants shared.

## **CHAPTER III**

### **RESEARCH METHODS**

A journey begins before the travelers depart. So, too, our grounded theory adventure begins as we seek information about what a grounded theory journey entails and what to expect along the way. We scope the terrain that grounded theory covers and that we expect to traverse. (Charmaz, 2006, p. 1)

This dissertation has indeed been an adventurous journey, and the current chapter maps the route that I traveled. The chapter begins with an outline of the overall research design and my justification for choosing this design. Second, the chapter includes descriptions of the study's starting place—details about the participants, WILD program, recruiting process, and informed consent. Next the chapter follows the path of data-collecting procedures—the interview and observation methods that I employed—and of data analyses—the constructivist grounded theory techniques that guided my exploration of participants' stories. The course of the chapter then takes an important detour into more abstract landscapes of ethics and validity and concludes with the choices that I made in presenting the study's results.

#### **Outline of Research Design**

Over the course of this research, I sought to learn how 21 Deaf or disabled women from different countries experienced their multiple identities, the empowerment process, manifestations of empowerment, and relationships among these experiences within their social ecologies. Within an interpretive-constructivist research paradigm (described in Chapter I), I conducted interviews with and observations of the women who attended MIUSA's Seventh International WILD program (Mobility International USA, 2013b) during and after the three-week program and explored their experiences using constructivist grounded theory analysis procedures (e.g., Charmaz, 2000, 2006, 2011).

Increasing an understanding of how Deaf and disabled women across the world experience empowerment could help with the design, implementation, and evaluation of policies and programs that aim to facilitate the empowerment of this heterogeneous and underserved population. As I contemplated research designs that might contribute to developing such a critical understanding, I considered Zimmerman's (1995) observation that "The development of a universal and global measure of empowerment is not an appropriate goal because it may not mean the same thing for every person, organization, or community everywhere" (p. 587). Quantitative measures that are sensitive to Deaf and disability identities within specific cultural contexts may indeed be useful in assessing empowerment processes and outcomes—for example, when evaluating the empowering effects of a leadership program. The lack of context-specific, disability-positive measures currently available, combined with the diverse cultural backgrounds and social locations of participants in the current study, led me to rule out quantitative methods, however. Moreover, using numbers to aggregate and generalize the identity and empowerment experiences of participants would fail to capture the richness and detail of participants' life experiences.

I chose qualitative and community-based, participatory methods to guide my research. Qualitative research methods are well suited to the task of exploring and describing complexity, contexts, and meanings (Leavy, 2017), a task that is particularly important when exploring such multidimensional and situated constructs as empowerment and identity. Community-based, participatory research methods involve power sharing—the close collaboration of researchers and participants throughout the research process (Leavy, 2017). Together, using qualitative and participatory methods

helped me navigate the complex, context-specific, and meaning-rich facets of participants' life experiences in a manner intended to be as empowering as possible.

### **The Starting Place**

**WILD participants.** I recruited participants for the current study from the selection of women who attended the Seventh International Women's Institute on Leadership and Disability (Mobility International USA, 2013b). The mission of the 2013 WILD program was to gather women leaders with disabilities from around the world "to strengthen leadership capacity, create new visions, and build international networks of support for inclusive international development programming" (Mobility International USA, 2013b, para. 3). The WILD participants included 21 women with a variety of disability experiences from 21 different countries. They ranged in age from 27 to 44 years old and traveled to Eugene, Oregon, from the following countries: Bangladesh, Barbados, Burkina Faso, Cambodia, Cote d'Ivoire, Ecuador, Ghana, India, Jordan, Kenya, Malawi, Mali, Mexico, Myanmar, Nepal, Pakistan, Peru, Philippines, Rwanda, Sierra Leone, and Zambia. On their applications to WILD, participants self-reported a range of disabilities; I do not intend these categorizations to stand in for their disability identities, however. On their applications to WILD, four women identified as Deaf, two as having psychosocial disabilities, and three as having visual disabilities. Twelve women reported experiencing some kind of physical disability, resulting from amputation, arthrogryposis, cerebral palsy, muscular dystrophy, polio, rheumatoid arthritis, or spinal cord injury.

Participants attended the WILD program from August 3-25, 2013. MIUSA staff members selected the participants for the WILD program by way of an application

process. The final delegation included women with disabilities who were educators and activists in civil society organizations or organizations led by and for people with disabilities or by and for women.

I chose to recruit dissertation study participants from the 2013 WILD delegation because they represented a diverse sample, both in terms of their disability identities and geocultural backgrounds. They also represented a multinational population of women with disabilities, which the UN identified as experiencing multiple discrimination and as in need of empowerment (Office of the United Nations High Commissioner for Human Rights, 1996-2016a). At the same time, MIUSA staff selected these women because they are leaders in their organizations and communities, and thus I believed they could provide important information about what empowerment looks like when it is working.

**The WILD program.** The 2013 WILD program (Mobility International USA, 2013b) was organized by MIUSA and sponsored by the United States Agency of International Development (USAID). The MIUSA offices are located at 132 East Broadway, Suite 343, in Eugene, Oregon. MIUSA is a United States based non-profit organization with a mission to “empower people with disabilities around the world to achieve their human rights through international exchange and international development” (Mobility International USA, 2013a, para. 4). USAID (United States Agency of International Development, 2013) works in over 100 countries to “promote broadly shared economic prosperity; strengthen democracy and good governance; protect human rights; improve global health; advance food security and agriculture; improve environmental sustainability; further education; help societies prevent and recover from



conflicts; and provide humanitarian assistance in the wake of natural and human-made disasters” (quote adapted from [usaid.gov](http://usaid.gov) website).

The WILD program has an explicit goal of empowering women with disabilities (Cindy Lewis, personal communication, 2012). In service of this goal and of the overall mission, the WILD program included interactive workshops, opportunities for participants to practice new skills, and on-site visits to educational and professional settings all around Eugene, including the University of Oregon campus. The program covered the following topics: (a) strategies for implementing national and international policies and legislation (e.g., the UN’s CRPD and the USAID Disability Policy); (b) education and the rights, opportunities, and practice of educating students with disabilities; (c) health and family issues, such as parenting, women’s health, HIV/AIDS, reproductive health, and violence prevention; (d) leadership strategies and skills; (e) using the media; (f) organizational development and sustainability; (g) inclusive international development; and (h) goals and action planning sessions, including plans for the transfer of information from WILD to other women and girls with disabilities in participants’ home countries. WILD also involved a number of cultural and team-building experiences, such as living with a local Oregonian host family, braving the Spencer Butte Challenge Course (City of Eugene, Oregon, 2013), rafting on the McKenzie River, cooking a meal together, and enjoying a dance party at the home of Susan Sygall, MIUSA’s CEO. The official languages of the 2013 WILD program were American Sign Language, English, and Spanish.

Prior to beginning this research, I had professional relationships of mutual respect with the MIUSA program staff. I had worked with them for four years on a variety of

projects and programs—initially as a summer intern and later as a volunteer—in Eugene, Oregon. I also worked with them as a participant on the United States-Jordan Young Women with Disabilities Leadership Exchange program, which took place in the Hashemite Kingdom of Jordan in September, 2012. I believe that we regard one another as disability rights advocates, who promote a strengths-based, sociopolitical understanding of disability in a world that still emphasizes an individualist, deficit-based model. MIUSA staff granted me permission to conduct interviews and observations during the 2013 WILD program so that I could provide information and insight about the participants' empowerment processes. Although the current study was not a program evaluation, the MIUSA staff tries to continue learning from participants to enhance the empowering environment of the WILD program and to refine the supports that staff offer once participants return home (Cindy Lewis, personal communication, 2012).

**Recruitment.** After obtaining approval from the University of Oregon's Institutional Review Board (IRB; protocol number 07022013.006), I began recruiting participants for the study. MIUSA staff included a brief description of my study in English and Spanish in the pre-departure packets that they emailed to participants in July (Appendix A). During the WILD orientation in early August, MIUSA staff granted me time to introduce myself to the group, to describe the study, and to answer questions. Participants also had an opportunity to approach me one-on-one during the afternoon break to ask more questions and discuss their interest in participating.

**Informed consent.** I verbally informed participants about the purpose, expected duration, and procedures of my study. On their first day of orientation and again at the time of each interview, I described the interview process, my intention to record their

voices, and my hope to work alongside them during and after their participation in the WILD program. I also explained their right to decline or to withdraw from the research at any time and provided assurances that their decisions not to participate in my study would not have any foreseeable effects on their interactions with me or with MIUSA staff.

I also shared what I believed to be benefits and projected risks of participating in the study. I had designed the study to invite Deaf and disabled women to discuss their empowerment experiences, and I hoped that the experience of telling their stories would feel directly beneficial and, to whatever extent possible, like a small, empowering experience in itself. In addition, I intended their stories to help inform empowerment and identity theory; enrich the understandings of Deaf, hearing, disabled, and nondisabled people; and provide useful information to the WILD program. Because this study was strengths based, I expressed my belief that it would pose minimal risk to participants. The only projected risks I foresaw were that the interviews might touch upon emotional and personal topics and that participants' stories about empowerment, identities, and environments might reveal their identities to MIUSA staff or to other people who were acquainted with the participants. To address risks, I planned to utilize my counseling skills to address any negative emotions that might arise during interviews and to make every effort to protect the identities of participants who requested confidentiality.

All 21 women decided to participate in the study, and I provided them each with an informed consent document to sign. I made the form available in printed English, printed Spanish, and uncontracted English Braille (refer to Appendix B for print versions

in English and Spanish). Participants also had the option to have the form read aloud to them or interpreted into American Sign Language.

The final section of the informed consent document gave participants an opportunity to choose among three confidentiality options: they could choose to (a) use their names and full identities in relation to their stories; (b) generate a pseudonym in relation to their stories, which would likely identify them to MIUSA staff and other people who knew them; or (c) request that all identifying information be disguised in the dissertation manuscript. They made decisions regarding their confidentiality preferences at the end of the initial interviews and again at the end of follow-up interviews.

### **Data Collection**

**Initial interviews.** I conducted semi-structured qualitative interviews with the 21 women who attended MIUSA's 2013 WILD program. The initial interviews addressed my research questions: how do the participants describe the experiences of their ongoing empowerment processes within various ecological systems, and how do participants' empowerment experiences relate to their salient, intersecting identities? More specifically, I asked participants how they became the activists that they are today, and I sought to explore the barriers and supports, as well as the various personal, professional, and sociopolitical contexts in which they had empowering (and disempowering) experiences. I interviewed each participant for at least one hour during her stay in Eugene, Oregon.

In order to accommodate the busy schedule of the WILD program, I conducted interviews sporadically in a variety of locations with the help of a great many people. The interviews took place in hotel rooms, host family homes, my apartment, in a backyard

under an umbrella, and in cabins on a campground outside the city of Eugene. I communicated and coordinated with MIUSA staff, host families, and drivers to schedule the 21 interviews. In seven of these interviews, I relied on and gratefully accepted the generous support of one Spanish language interpreter, three ASL interpreters, and two Certified Deaf interpreters (CDIs). A CDI is a certified specialist and Deaf person who provides interpreting, translation, and transliteration services in sign languages and in other visual/tactile forms of communication; CDIs facilitate a level of linguistic and cultural bridging that is often not possible to achieve when hearing ASL interpreters work alone (National Interpreter Education Center, 2018). One of the French- and English-speaking participants also asked for a little extra language support, so we invited my French-speaking neighbor to join us for one of the interviews. I audio recorded all but one interview and hired a TypeWell-transcriptionist to transcribe the recordings into text. The people who assisted me as interpreters, translators, transcriptionists, and research assistants all signed confidentiality agreements (Appendix C).

Throughout the project, I utilized responsive interviewing, an approach to in-depth qualitative interviewing described by Rubin and Rubin (2012). The essence of responsive interviewing included (a) selecting knowledgeable interviewees, such as the WILD participants who were already engaged with topics of identity and empowerment in their activist work, (b) listening carefully to their accounts, and (c) asking new questions based on the answers they provided. Responsive interviews tend to focus in depth on a topic, rather than exploring a wide range of topics.

Within responsive interviewing, interviews are semi-structured with open-ended questions. Researchers plan some key interview questions in advance (refer to

Appendixes D and E for initial and follow-up interview outlines in English), and organize the questions so that they connect to one another (Rubin & Rubin, 2012). The questions allow flexibility for following a participant's lead within each interview.

**Participant observations during the WILD program.** When I was not conducting interviews, I spent time as a participant observer on the WILD program to learn more about the program activities, atmosphere, and participants. I centered my observations around issues of identity and empowerment among the individual participants and within the group as a whole. To the best of my ability, I wrote brief field notes while I was on program during the days and extended them into fuller contact summaries and analytic memos in the evenings. As a blind participant observer, my observations were auditory, kinesthetic, and experiential. As with any participant observer, my perspective interacted with and informed the phenomena that I researched (e.g., Emerson, Fretz, & Shaw, 2011). Although I do not report results from participant-observations to a great extent in this dissertation, my accounts of participants' identity and empowerment experiences are informed by and reflect the perspective that arose out of my observations.

**Follow-up interviews at home and abroad.** Because the initial interviews with participants were dispersed over the course of the three-week WILD program, I sought to touch base with each participant by Skype, email, or Facebook within the first month after she returned home. My intention was to offer an opportunity for participants to debrief their experiences of the WILD program in its entirety and to seek any support that they might need upon reentry to their home countries. I also tried to maintain casual contact with participants as I prepared to conduct follow-up interviews. The purposes of

maintaining ongoing contact were (a) to seek clarifications to the content of our initial interviews, (b) to provide support and appreciation as participants continued with their activist work, (c) to maintain rapport, and (d) to prepare access and communication strategies for the follow-up interviews.

I conducted longer, more formal follow-up interviews, which continued the focus on empowerment and identity, with 16 of the 21 participants. The interviews took place between five months and two years after participants completed the WILD program. In these interviews, I asked participants more about how they experienced empowerment during the WILD program in Eugene, Oregon and how they experienced empowerment in their home countries. I also tried to follow up on themes that arose during the initial interviews and sought to understand these themes in greater nuance as participants returned to familiar environments and relationships.

The follow-up interviews transpired in a variety of formats and languages. Five interviews took place over Skype, one by phone, five via email, one in a Facebook chat space, and four in person—depending on participants' preferences and internet connectivity. Altogether, we used ASL, English, French, Malian Sign Language, and Spanish during the interviews. I employed a CDI, utilized a Video Relay Service, and hired French and Spanish interpreters/translators to assist me during and after interviews. I also took advanced Spanish language classes so that I could conduct follow-up interviews with Spanish-speaking participants directly in Spanish. I audio recorded all of the Skype and phone interviews and continued working with a TypeWell-transcriptionist who transcribed the recordings into text.

**Community observations and conversations.** Traveling to the home countries of three participants offered an important opportunity to understand the barriers and facilitators to empowerment that these participants regularly experienced in their home communities. As someone who presents as a blind woman, I was able to make observations by living some of the gender and disability experiences alongside WILD alumnae for a short while, which helped contribute to the complexity of my understanding. Lived, in-person experience tends to be the most effective way for me to engage in observational research, so I also sought out this opportunity to help me learn about the aspects of empowerment, identity, and culture that I do not share. Moreover, I thought that important others in participants' lives might have keen insights into participants' empowerment processes, and I planned to consider informal conversations with these family members, colleagues, and friends to be part of my observations. I utilized informed consent processes appropriate to observational research (Appendix F) and submitted amendments to my IRB application as I solidified my travel plans.

Deciding whom to visit for the purposes of the current study was particularly difficult, and ultimately a variety of factors, such as timing, expense, and personal barriers, influenced my choices. In the spring of 2014, I visited Lizzie, who identified as a mother, wife, and business woman with a physical disability, in Nairobi, Kenya. Lizzie was in the process of starting up a disability consultancy (This-Ability Consulting, 2017) to inform organizations and employers about disability rights and access. On the same trip, I visited Charity, who identified as a community leader, mother, wife, and survivor with a psychosocial disability, in Kigali, Rwanda. Charity lived through the 1994 genocide and co-founded the National Organization of Users and Survivors of Psychiatry



in Rwanda (n.d.), an organization to support, advocate with, and protect the rights of people with psychosocial disabilities. In the summer of 2014, I visited Maru, a graduate student, Orientation and Mobility instructor, teacher, and activist with a visual disability in Cuenca, Ecuador. Maru worked tirelessly to promote inclusive education, access, and disability rights in all of her roles and still found time to have a vibrant social life, which was important to her.

**Member checks and debriefing.** I sought to engage in member checks, or respondent validation, throughout the study. I shared initial and follow-up interview transcripts with participants and invited their corrections and clarifications. As I completed results chapters, I posted to a WILD 2013 Facebook group, offering to send copies of the results to anyone who was interested in reading them or providing feedback. I incorporated all of the corrections and suggestions that I received.

### **Data Analysis**

In the current study, I adapted constructivist grounded theory research methods to guide the explorations and analyses of participants' stories. In the introduction of *Constructing grounded theory*, Charmaz (2006) extended metaphors of following data trails, scaling analytic cliffs, and securing one's self with a taut rope to the data on solid ground. Far from overly dramatic, these descriptions aptly described the adventure of joining others on their life journeys, an adventure I was eager to undertake. Moreover, some researchers have argued that constructivist research methods are particularly well-suited to investigating the dynamic and complex nature of the empowerment process (Foster-Fishman, Salem, Chibnall, Legler, & Yapchai, 1998), another advantage of using Charmaz's grounded theory. Constructivist grounded theory is a flexible, systematic

method of data analysis, which involves jointly collecting and analyzing data and includes specific tools to elucidate participants' meanings and to construct theoretical frameworks (Charmaz, 2000, 2006, 2011). The strategies of grounded theory include (a) collecting and analyzing data simultaneously, (b) coding data in a two-step process, (c) using comparative methods, (d) writing memos to develop the construction of conceptual analyses, (e) sampling to refine the emerging theoretical ideas, and (f) integrating the theoretical framework (Charmaz, 2000).

**Collecting and analyzing data simultaneously.** Grounded theorists typically analyze data as they collect them (Charmaz, 2000, 2006, 2011). While interacting with the data, researchers can pose questions to ask in subsequent interviews. As their focus and questions sharpen, they can determine how to continue sampling participants.

Simultaneous data collection and analysis were not possible in the current study, however. One reason was that the busy schedule and three-week time-frame of the WILD program offered limited time to conduct initial interviews with participants, let alone analyze them. A significant time lag also occurred while the TypeWell transcriptionist transcribed the recorded interviews into text. Consequently, I conducted several follow-up interviews before the participants had an opportunity to review the initial transcripts. Additionally, I learned mid project that all of the qualitative data analysis software programs on the market were inaccessible with JAWS for Windows, the screen-reading software that I use. By the time I thoroughly investigated the available options, came to this sorry conclusion, and found sighted readers to assist me, I was only able to begin systematically analyzing the data part way through conducting the second wave of interviews.

I fostered the spirit of grounded theory, however, even as I made adaptations to my research methods. The specific, finite sample of participants to which I had access obviated the task of simultaneous data collection and analysis because I did not intend to continue seeking new participants for the study. With regard to informing follow-up interviews, I referred to the contact summaries and journal reflections that I wrote during the WILD program, listened to recordings of the initial interviews, and wrote memos outlining preliminary analyses. I also received feedback from participants during member checks that contributed to the evolution of interview questions and data analyses.

**Coding data in a two-step process.** Because I did not have immediate access to qualitative data analysis software, I began by exploring the interview transcripts in Microsoft (MS) Word 7. Charmaz (2000, 2006, 2011) recommended coding texts line by line, but because I began coding by listening, I started by coding the shortest meaning units that made sense to me as I navigated the text with my screen-reading software. This incident-by-incident coding involved assigning shorthand action labels to each segment of text in the form of gerunds—phrases that end in *ing*—much like the phrases in the subheadings of this Data Analysis section. This process allowed me to become familiar with the texts and to begin formulating meanings and making comparisons.

After investigating my own access barriers, I began hiring sighted readers to help me access NVivo 10 and 11—qualitative data analysis software—to manage and sort the data. The use of NVivo helped me examine interview transcripts more closely and methodically than my use of MS Word. This second step of the coding process, what Charmaz (2000, 2006, 2011) called focused coding, involved organizing and synthesizing large amounts of data into categories and themes. This type of coding was more

conceptual than the initial, incident-by-incident coding (Charmaz, 2000). The intention of sorting and synthesizing data is to lead to possible explanations to inductively build ideas into nascent theory (Charmaz, 2000).

Because ecological and intersectionality theories framed my study, I created a primary and secondary coding structure—content codes and context codes—to help me layer my analyses. The primary or content codes represented analyses that were grounded in the content of participants’ stories—what they were doing, thinking, feeling, experiencing. The secondary or context codes represented the ecological systems in which the stories occurred (e.g., family, school, physical environment/infrastructure, sociocultural context) or the background topics that participants discussed (e.g., civil and human rights, education, identity, empowerment and strength). I hoped that this double-layered coding would assist me in sorting, contextualizing, and analyzing the multiple overlaps and intersections among the codes (refer to Appendixes G and H for comprehensive lists of content and context codes).

**Using comparative methods.** Making comparisons is a major part of grounded theory (Charmaz, 2000), though I preferred to think of this process as making connections rather than as making comparisons. As I sorted and synthesized my codes, I sought to make connections among the situations, experiences, perspectives, and behaviors of different participants. Within each individual’s accounts, I sought to understand data from multiple points in time. I tried to think about data in relation to categories and about the categories in relation to one another, and I considered discrepancies and counterexamples.

**Writing analytic memos.** Recording extended notes or memos (by typing on the computer and by making voice recordings) gave me an opportunity to flesh out my comparisons/connections and categories in detail, as Charmaz (2006) recommended. Within grounded theory, memo writing is an intermediate step between coding and the first draft of a completed analysis (Charmaz, 2000). Through my memos, I hoped to elaborate the processes, assumptions, and actions that appeared in my codes, make connections, and expand my ideas. The intention of coding and writing is to assist the researcher in raising some of the focused codes to conceptual categories (Charmaz, 2000, 2006, 2011), and indeed, I found that I gained a fuller understanding from writing and talking about my analyses throughout the dissertation process.

As I considered the codes and wrote memos, ecological and intersectionality frameworks guided my analyses. I attended to the ways in which participants experienced and constructed identity in their talk and how multiple social locations shaped issues of access-inclusion, discrimination-stigma, and empowerment. I also used memos to help articulate the complexity of my own identity, to locate myself with respect to the issues that participants raised, and to consider experiences of insider, outsider, and spaces in between.

**Employing theoretical sampling.** Typically, as grounded theorists refine their categories and develop them as theoretical constructs, they go back to the field and collect additional data to fill any gaps in their data and/or theories (Charmaz, 2000). Although the scope of this dissertation precluded the possibility of sampling beyond the 2013 WILD participants, the analyses and theory that emerged from the current study might inform follow-up interviews and observations with additional participants in future

studies. If I am fortunate enough to continue working with these 21 women activists in the future—something I would greatly enjoy—the ongoing refinement of theoretical ideas could help me decide which individuals and communities to visit next and how to deepen the exploration of identity and empowerment. Indeed, Charmaz (2000) affirmed that some researchers never reach data saturation—the point at which newly collected data stop suggesting new categories or relationships; she encouraged researchers to return to their rich data time and time again.

**Integrating the theoretical framework.** As discussed in Chapter I, the current research transpired within an interpretive/constructivist research paradigm (Guba, 1990; Leavy, 2017; Ponterotto, 2005). Thus I did not seek to explain how empowerment and identities manifest, interrelate, and generalize within a single, objective reality. Instead, I utilized research methods that could ultimately help me begin developing theory about how some Deaf and disabled women from across the world experience and make sense of empowerment and identity within different material and social environments. Consistent with the paradigm, I also took a reflexive stance and sought to articulate, as best I could, the ways in which my own values and experiences informed the research process from study design through data analysis.

### **Ethical Issues**

Ethics are at the very core of social research and underlie every stage of the research process from start to finish (Leavy, 2017). Over the course of this study, I adhered to the ethical research standards as outlined by the APA (American Psychological Association, 2017). In Chapter I, I addressed philosophical and reflexive dimensions of ethics by enunciating my background and value orientations. In the current

chapter, I attended to procedural ethics by describing my methods of applying for IRB approval, acquiring informed consent from participants for conducting the research and recording their voices, protecting participants from any adverse consequences of choosing not to participate, and debriefing participants as part of member checks of the interviews and chapter drafts. Here I raise two additional issues of procedural ethics—confidentiality, and the act of collecting data from significant others.

**Confidentiality choices.** Maintaining confidentiality in this study presented some complicated ethical issues. Participants shared personal stories about their intersecting identities, information about the unique environments in which they lived, and accounts of their empowerment (and disempowerment) experiences. Even with the use of pseudonyms or the aggregation of participants' responses in a final report, these data are by their very nature identifying and would take considerable effort to disguise, particularly to MIUSA staff and others who know the participants well. Moreover, because these stories were rich in self-definition and empowerment strategies, I wanted the WILD participants to have the rights to their interview transcripts and the option to claim their stories and use their true names. Thus I offered participants the option to use their names and full identities in relation to their stories, generate pseudonyms, or request that all identifying information be disguised in my reports and communications about the study. I actively inquired about participants' confidentiality preferences at each phase of the study and de-identified their transcripts until they specified otherwise. Even offering participants these three levels of confidentiality had potential drawbacks, however, because, depending on the number of participants who chose to protect versus reveal their names, the remaining participants who did not wish to use their names had a chance of

becoming identifiable by default. I worked hard to consider this possibility as I wrote the results chapters and made decisions about which excerpts of participants' stories to share.

**Collecting data from significant others.** Another ethical dilemma involved holding informal conversations with important others in participants' lives. Learning others' insights regarding participants' stories and empowerment processes provided valuable perspectives, whether the perspectives came from MIUSA staff and volunteers or from the families, friends, and colleagues in participants' home communities. These informal conversations contributed to validity by strengthening triangulation of data in the current study. That said, this prospect also raised ethical dilemmas. Even though I did not transcribe or analyze these types of informal conversations, I had to think and act carefully to ensure that holding these conversations did not extend beyond the verbal informed consent procedures that the IRB required for community observations. I did not want to engage significant others as participants in their own rights, and I had to be aware of the extent to which these important others might have different and/or competing interests with those of the WILD participants.

**Integrating ethics.** I sought to integrate a consideration of ethics throughout the design, conduct, presentation, and dissemination of this research. In Chapter VII, I reflect more on relational ethics and relations to power, discussing the ways in which my ethical principles and procedures—values and practices—did and did not align. I believe that the ongoing examination of ethics is at the heart of the empowerment process, particularly when working with Deaf and disabled women from the Global South, whose stories and perspectives have historically been dismissed, derogated, or colonized.



## Validity

A discussion of scientific and psychopolitical validity is a vital backdrop to the delineation of my research methods. The interpretive or constructivist paradigm in which my study transpired influenced my understanding of scientific validity and the work of Prilleltensky and colleagues inspired my focus on psychopolitical validity (e.g., Morsillo & I. Prilleltensky, 2007; I. Prilleltensky, O. Prilleltensky, & Voorhees, 2009). Thus in this section, I state my priorities regarding scientific validity, describe psychopolitical validity as an additional consideration, address validity threats to the study, and outline the specific techniques that I employed to address validity threats.

**Prioritizing validity criteria.** Whittemore, Chase, and Mandle (2001) reviewed the literature and provided a synthesis of validity criteria: “The standards to be upheld as ideals in qualitative research” (p. 528). From an interpretive/constructivist perspective, researchers argue that a single set of scientific criteria for what constitutes valid knowledge does not exist. The researcher’s judgement, therefore, must determine which of the validity criteria to prioritize in a given study (Whittemore et al., 2001).

Based on the mandate proposed by Whittemore et al. (2001), I prioritized validity criteria of credibility, authenticity, criticality, integrity, explicitness, vividness, sensitivity, and congruence for the purposes of this study. In other words, I sought to reflect the experiences of participants in a believable way (credibility); to demonstrate an awareness of the subtle differences in the constructions and voices of participants (authenticity); to explore alternative interpretations, discrepancies, and my own biases (criticality); and to report my findings humbly after repetitive validity checks (integrity). Whittemore et al. identified these first four criteria as primary validity criteria within

qualitative research. In addition, I strove to articulate my methodological decisions, interpretations, and personal biases (explicitness); to gather and render rich descriptions in a manner appropriate to individuals, cultures, and social contexts (vividness and sensitivity); and to strive for consistency among my research questions, methods, and results (congruence). I drew this second set of criteria from a list that Whitemore et al. identified as secondary criteria that can arise with regard to specific study designs.

Psychopolitical validity is another concept relevant to this study because this form of validity addresses the degree to which researchers and activists consider power dynamics in psychological and political domains (Morsillo & I. Prilleltensky, 2007). “Power is a central construct in wellbeing” (I. Prilleltensky et al., 2009, p. 357) and central to this dissertation. I. Prilleltensky and colleagues divided psychopolitical validity into epistemic and transformational psychopolitical validity (e.g., Morsillo & I. Prilleltensky, 2007; I. Prilleltensky et al., 2009). Epistemic psychopolitical validity applies primarily to research and refers to the extent to which researchers consider the role of power on multiple ecological levels. Transformational psychopolitical validity applies to interventions and refers to the actual changes that take place in both psychological and political domains. With regard to the current project, epistemic psychopolitical validity, in particular, was another priority that I identified in designing the study, conducting interviews, analyzing the data, and presenting results.

**Addressing validity threats.** Maxwell (2013) articulated two main types of threat to validity: researcher bias and the effect of the researcher on participants, both of which played a notable role in my study. My biases, or subjective standpoint, continuously interacted with my research due to my intersecting identities and social location, to the

mixture of privilege and disprivilege that have shaped my perspectives, and to my individual experiences and personal history. My task within an interpretive/constructivist research paradigm was not to eliminate my biases, which I believe impossible, but to interrogate them at each juncture so that I could better understand how my subjective stance interacted with participants and minimize the extent to which my biases covertly directed my inquiry and data analyses. Reactivity, or the influence that I had on participants, was also strongly present in my project because I interacted directly with participants throughout the study as an interviewer, participant observer, and, ultimately, a person who came to care deeply about each one of them. The "consequential presence" that can link to these reactive effects does not need to be a contamination of what researchers observe and learn (Emerson, Fretz, & Shaw, 2011, p. 4). In the current study, for example, I worked to consider my potential influences and tried to create positive and supportive opportunities for participants to share their experiences. I thus hoped to eliminate some of the negative consequences that can result from reactivity and stay true to an interpretive/constructivist paradigm, within which researchers tend to consider influences of the researcher to be inevitable and to think carefully about the content and consequences of those influences .

Whittemore et al. (2001) discussed validity techniques as methods that researchers can employ to diminish validity threats to their research designs, as well as to the collection, analysis, and presentation of data. With regard to my study design, I used validity techniques of presenting a rationale for sampling, prioritizing the perspectives and authorship of participants, and factoring in some triangulation—the process of collecting data from diverse individuals and settings using multiple methods, such as

interviews and observations (Maxwell, 2013). With regard to data collection, I articulated my data collection decisions and generated verbatim transcriptions of each interview. Concerning data analysis, I articulated data analysis decisions, employed member checking, used NVivo to help me manage and sort data, continued reviewing the literature as my codes and categories emerged, wrote memos, and engaged in self-reflection. Finally, as I present, interpret, and discuss the data in subsequent chapters, I offer evidence to support my interpretations via direct quotes from participants, acknowledge my own perspective, highlight power dynamics, and provide rich descriptions where I can.

### **Presentation of Results**

The results of this study extend into three chapters. Chapter IV offers sketches of individual participants, exploring how the forms and functions of their salient, intersecting identities operate in their life stories. It also includes a brief exploration of the themes of normality and alterity that arose in participants' identities. Chapter V addresses the journey of empowerment. In particular, it focuses on the role of critical awareness, as well as on the barriers that impeded and the supports that facilitated participants' empowerment journeys. Chapter VI reports many different empowerment experiences. Specifically, it presents (a) participants' strategies for cultivating personal empowerment and (b) various manifestations of empowerment in the forms of inner fortitude and strength, of connection and collaboration, and of actions toward self-advocacy and social justice.

As part of honoring validity criteria of integrity and explicitness, I wish to articulate a few choices that I made in reporting the results. Here I discuss how I chose to

represent participants' direct quotes, to map complex identities, and to identify manifestations of empowerment. I reflect on the effects of some of these choices in Chapter VII, the discussion chapter.

**Representing participants' perspectives.** Validity criteria of authenticity and sensitivity played important roles in my decisions about how to represent and report participants' direct quotes. I considered my obligations to present participants' quotes sensitively without homogenizing them or erasing cultural differences (Leavy, 2017). After some trial and error and conversations with participants over member checks, I decided to seek a balance between conveying participants' individual expressions as closely as possible and honoring their values of representing themselves with professional clarity. I also took into consideration that participants used many different signed, spoken, and written languages over the course of our interviews and that I engaged the services of many different interpreters, both professional and amateur. Reporting participants' exact language use, therefore, seemed less possible, less representative, and less important to the study than seeking to preserve the content, style, and spirit of participants' stories. That said, I did not make many changes to participants' direct quotes as they were spoken, written, or interpreted to me. I eliminated false starts and some paralinguistic fillers, such as "um" or "you know," and changed some prepositions and verb conjugations to support the clarity or consistency of the excerpts that I pieced together and included in the results. I also included some clarifications and comments in square brackets to facilitate the reader's understanding. I hope the resulting stories and quotes successfully evoke the validity criterion of vividness for the reader.

**Using citations in the results.** As part of adhering to ethics of beneficence, responsibility, and justice (American Psychological Association, 2017), I sought to benefit participants in whatever small ways I could. One way that I could pursue responsibility and justice was to provide references for the disability and social justice organizations with which participants were involved. Wherever possible, I include citations throughout participants' identity stories in Chapter IV so that readers can learn more about these organizations and about how they might offer support.

**Organizing identity processes.** During their interviews, participants shared such intricate pictures of their salient, intersecting identities that I needed to develop a consistent method of thinking about and discussing them. Throughout Chapter IV, therefore, I regularly use a few specific terms to articulate how each participant's identities appeared to operate in relation to one another and to her overall narrative. I intend this organizational model and my analyses to reflect only the identity configurations as they appeared within participants' interviews. Deeper analyses of how participants understand their own complex identities and how those identities interact with one another are beyond the scope of this study.

In reporting identity results, I write about identities as generating or organizing each other, as developing over time, as interacting with one another, or as intersecting at a focal point. According to this organizational method, identities are generative or organizing when they create, shape, arrange, or encompass other identities. For example, in telling my own story, I might describe how my identity as a disabled person has helped organize my student identity, and I might explain how the barriers I have experienced as part of living my disability and student identities have generated and organized my

activist identity. I discussed an identity as developmental when a participant described its changes over time. For example, my story could trace the development of my identity as a sick person as it changed over the course of my time in graduate school. According to my organizational method, interacting identities are identities that intersect and mutually influence one another over time or at multiple key points in a participant's story. In describing my experience of conducting dissertation research, I could certainly share how my sick, disability, student, and activist identities interacted with one another throughout the process. Finally, I refer to participants' identities as intersecting when I seek to draw attention to the context or moment in which two or more identities overlap and influence each other. I might talk about the oral defense of my dissertation as such a moment when many aspects of my identity intersected and (hopefully) overlapped with an experience of empowerment.

**Describing terrains over pathways.** Chapter V addresses the empowerment process or journey. In this chapter, I do not seek to outline a general path or even individual paths to empowerment. Instead, Chapter V focuses more on the terrain of the empowerment journey and some of the major features or landmarks (barriers and supports) that participants encountered. The reader can infer some information about participants' pathways to empowerment by reading their identity stories in Chapter IV.

**Reporting manifestations of empowerment.** In Chapter VI, I make choices about how to report components or manifestations of empowerment. I classify participants' approaches, experiences, and actions as manifestations of empowerment (a) when participants explicitly labeled them as such or (b) when these examples illustrated participants' power to cultivate inner strength, to engage in action, or to work with others.

These components represent a broad overview of the empowerment outcomes that participants identified as most meaningful.



## **CHAPTER IV**

### **RESULTS: SALIENT, INTERSECTING IDENTITIES**

The purpose of this research was to learn about the experiences of 21 Deaf or disabled women activists, particularly with regard to empowerment and identity, and the findings were as multilayered and complex as the participants themselves. In short, participants wove themes of identity and empowerment around and through important tellings of their stories, articulating perspectives that ranged in scope from individual to macrosystemic levels. All 21 participants discussed passions and interests that included but were not limited to access/inclusion, civil and human rights, communication and cooperation, empowerment and strength, Deaf and disability issues, personal sovereignty, parenting and families, and women's issues. As they described their salient identities, empowerment journeys, and empowerment experiences, participants shared their emotional and physical responses—doubt, gratitude, grief, exhaustion, fear, hope, joy, loneliness, love, outrage, pain, pride—to the various twists and turns of their life stories (refer to Appendixes G and H for a full listing of the codes and categories that emerged from the interviews).

The current chapter, which is the first of three results chapters, addresses the topic of identity. Because each participant's identities were uniquely meaningful and intersected in unique ways, the vast majority of this chapter focuses on individual participants and on the intricate ways in which their salient identities overlapped, interacted with, and/or developed alongside each other in various contexts. Next, the chapter addresses the themes of normality and alterity that arose in participants' stories.

The chapter concludes with a brief preview of the empowerment results in Chapters V and VI.

### **Salient, Intersecting Identities**

In this section, I offer biographical sketches of individual participants and highlight salient aspects of their identities as they emerged and intersected during our interviews together. I begin by introducing Charity, Lizzie, and Maru, the participants whose homes I visited and with whom I spent the most time. I then discuss Nandar, with whom I also had two in-person interviews, and continue with some additional participants in alphabetical order, according to their first names/pseudonyms. I conclude with a brief reflection about the configurations of participants' identity stories and the relationship between participants' identities and their social ecologies. In these sketches of participants' identities, I do not include the participants who chose to remain anonymous. All of the participants' direct quotes have been translated into English.

Each participant told her unique story in a unique style. Some participants spoke explicitly and some indirectly about their complex identities. Some outlined developmental trajectories while others described a more kaleidoscopic perspective. Some participants shared intimate details of their experiences and others offered more abstract or philosophical reflections. In structuring their stories and selecting direct quotes, I seek to honor participants' styles and to highlight prominent themes without comparing or contrasting their individual experiences. As explained in the Research Methods (Chapter III), I have conceptualized each participant's multiple identities as generating, organizing, mutually influencing, and intersecting with one another within

particular contexts and developmental moments, and I try to be consistent about articulating these conceptualizations.

Where I consider it useful, I supplement participants' stories with some of my personal observations and information that I gathered about participants' ecological contexts. My travels and research offered me helpful background information to contextualize participants' self-described experiences, and participants shared a number of resources with me that they deemed important. Thus I include some citations of articles and websites in this chapter. Because my observations and impressions are steeped in my own cultural background, I strive to share my impressions as overtly as I can with the reader. Although I try to organize participants' autobiographical sketches according to patterns that I observed in their stories, formulating introductory statements about the participants naturally privileges some of their identities over others. Therefore, I consistently state gender, disability, and geographic indicators, alongside some of my personal impressions, as I introduce each participant and her story. In the introductory paragraph of each participant's biographical sketch, I also mention identity markers that arose during our interviews but upon which the participant did not expand. I dedicate the remainder of each sketch to outlining the story and identity configuration that participants described in our interviews.

**Content warning.** In their stories, some of the participants described physical, sexual, or emotional violence that they either witnessed or experienced. I share quotes from their experiences that some readers may find upsetting. I try to precede such descriptions with a brief acknowledgement of the violence to come.

**Charity.** Charity, a woman with a psychosocial disability living in Kigali, Rwanda, brought an earnest, serious, and powerful energy to her personal, professional, and religious life. During our time together in the United States and Rwanda, I deeply appreciated her hospitality, admired her resourcefulness, and connected with her around her passion for mental health and wellbeing. Born in Uganda like many Tutsi people whose families sought to escape the 1959 Hutu revolution, Charity was visiting family in Rwanda in the spring of 1994 when the genocidal violence began. At the time of our first interview, she was 34 years old and serving as the women’s representative at the National Organization of Users and Survivors of Psychiatry in Rwanda (n.d.). We conducted our interviews in English, though Charity also speaks Kinyarwanda and Swahili. Over the course of our two in-person interviews and additional conversations together, Charity discussed salient aspects of her identity, which included being a survivor of genocide, having a psychosocial disability, and being a woman, Tutsi, leader, family member, and Christian.

Charity’s disability identity grew out of her experience living through the 100-day Rwandan genocide and connected inextricably with her identities as a survivor and a Tutsi. Charity identified as Tutsi on both her mother’s and father’s sides of the family. During my visit to Rwanda, Charity’s husband discussed the country’s history with me, explaining that the Tutsis were a historically royal social class—perceived as a superior race/ethnicity by European colonizers of Rwanda—who were targeted during the Rwandan genocide. At the Kigali Genocide Memorial (2016) museum, which I visited in March, 2014, the displays outlined the historical and systemic factors that led to racism, social unrest, revolution, and genocide in Rwanda—including socioeconomic disparities

in the 19th century and divide and conquer strategies on the part of Belgian colonial occupiers. While in Rwanda, I observed and/or participated in a number of ongoing reconciliation efforts, ranging from the sharing of stories sponsored by the Hope and Peace Foundation (2016) to umuganda, a national monthly community clean-up effort (Rwandapedia, 2016). I noticed that some of the reconciliation efforts encouraged people to privilege a national Rwandese identity over the Hutu, Tutsi, and Twa identities that factored into the genocide. Therefore, I asked Charity if she had experienced a shift in her identity as a Tutsi, and she replied,

I consider myself a Tutsi. I can't even change. Whether someone likes it or not, I will die when I'm a Tutsi. . . . My father died because of his identity that he was a Tutsi. The whole of my family, they died because of their identity that they were Tutsi. So even me, I can't change my identity.

During our interviews, Charity identified as a Tutsi survivor and shared a harrowing story of living through incredible violence at the age of 14.

They were using pangas, hoes, guns, everything, long sticks in private parts, raping women. Everything bad happened. I was so young, but I witnessed everything. . . . Dogs could come and eat someone you knew. . . . Children were being killed and they would say, "Forgive me." They could die when they are saying, "Forgive me. I will never become a Tutsi."

Charity also experienced significant violence herself, which contributed to her survivor identity.

I had injuries over here because they cut me over here. . . . You can touch me. You can touch the hole in my body [she placed my hand on a large scar on her abdomen]. . . . So I was moving with my blood. But I brought a cloth and tied it myself so that it could allow me to move without my intestines to come out.

She survived by hiding, terrified and injured, under a bridge for approximately one week at the height of the war.

When it was coming to the night, I would run to these small gardens of the villagers, and I could get fresh cassavas. I ate them when they were not cooked.

Then I could get some water somewhere, rainwater and drink. Then I went back to that bridge.

Even her rescue was a frightening experience that factored into her survival story.

She described meeting the soldiers who saved her.

When they came, they saw someone in a bridge, and they came to me. . . . At first, I feared to come out because I was thinking that even them, they're going to kill me. . . . And then someone came and put their hand on my hand and said, "You are who?" I said, "I'm Charity." "And why are you here?" I said, "I'm hiding myself." . . . I said, "I don't know you, maybe you are the killer." He said, "No I'm not the killer, but I can make you survive."

When Charity finally agreed to come out and go with the soldiers to a shelter, she encountered more grisly images to haunt her. "There were so many people, so many bodies. Everybody was having blood. They were all injured."

Charity named her disability "psychosocial disability" and described how it arose from her trauma experiences and began to affect her at the end of the war.

In fact, it started when we went to a burial, where we buried our relatives. They were all buried in the same place called Nyanza. This is where royal people come from. It is in southern Rwanda. So after burying them, this is the time when I started my crisis. . . . I would just fall down, like epilepsy. . . . When I moved, there were times when I would bypass where I was supposed to go. There's a time when I would just keep quiet the whole day without talking. This is where it started.

An important moment in the development of Charity's survivor and disability identities occurred several years after the war, as she began to find community and work toward social change as a leader. "We started having some people coming to us, telling us, this is not the end of your life. You have to come meet other people. You have to talk. . . . You have to have conversation with others." Charity began to emerge from her time of isolation and to meet other people who identified as having psychosocial disabilities. In 2005, she and three colleagues traveled to Uganda to visit an organization of and for

people with psychosocial disabilities. When they returned home, they founded the National Organization of Users and Survivors of Psychiatry in Rwanda (n.d.), a disabled people's organization (DPO) that advocates for appropriate services, opportunities, and human rights of people with psychosocial disabilities. Starting this organization involved considerable effort for many years, as Charity and her colleagues sought office space and resources and traveled to other countries to learn about other organizations. Thus began her history of grassroots organizing.

When I was young, I was heading the youth at the district level. Then from there, I was heading women at the provincial level. . . . Now I have like five hundred fifty people who have psychosocial disability, who at least know that "Charity is behind us." That makes me so strong.

Charity described herself as "a leader in my own organization," a professional identity that was largely organized by her identities as a woman survivor with a psychosocial disability. In her role of women's representative at the National Organization of Users and Survivors of Psychiatry in Rwanda (2018), she led a wide range of projects concerning women with psychosocial disabilities throughout the country. Much of her activism work focused on women. She collaborated with organizations such as the National Union of Disabilities' Organizations of Rwanda (2014) and The Association of the Widows of the Rwandan Genocide (refer to Gruber Foundation, 2011, for a description of the organization in English), organized peer support groups for women with psychosocial disabilities across the country, set up community support networks such as child care and advocacy for women in crisis, established a women's resource center to provide therapy and skills training, advocated for health insurance for women and indigenous people with psychosocial disabilities, and taught daily living skills to cross-disability groups of women. She has represented her

organization at conferences of the National Union of Disability Organizations of Rwanda (2014) and the World Network of Users and Survivors of Psychiatry (2013).

Charity's identities in relation to her family were complex: the violent deaths of her family of origin haunted the present-day life that she built with her husband and children. During our interviews, she described experiencing ongoing grief and horror around losing her father, brothers, grandfather, and aunties to the genocide and recounted the torture and murder of her grandfather to help illustrate her psychic pain.

I had my grandpa, who was staying in a palace because we are born in a royal family. So what they did . . . they put him in a pit . . . and they told him . . . “Your big eyes, they are going to be bitten by the birds.” So they left him there. . . . He died asking water for drinking. Whenever he would ask water for drinking, they would just come and urinate on him.

These images and memories intruded on her current family life and left her feeling lonely at times.

Although I'm married, there is a time when you think you could have someone who is from your family [of origin] and tell her or him what is happening to you. I have this challenge that I have nobody to tell.

Charity explained that she derived both intense stress and comfort from the intersection of her family, disability, and survivor identities. The psychosocial stress that she experienced at this intersection included financial strain and frantic efforts to pay for her children's school. She also referenced the ways that noise or any interpersonal conflict in her home could trigger her anxiety.

When I get some difficulties in my own family, this is where I get some mental crisis, because, what I hate is someone to give a burden to me, maybe quarreling. . . I don't like that because it makes me think different: [in those moments] I feel like dying is better than staying on that path.

At the same time, her family, survivor, and Christian identities intersected in ways that brought her comfort and strength. “But I'm strong now. I'm strong because when I pray



with my children, it gives me hope that I'm still surviving, yes."

Charity's identity as a Christian helped her to navigate and organize her survivor, disability, and leader identities.

When I go to church, this is where I find my peace. In a week, I take two days, Thursday and Sunday. Those two days, I'm supposed to go to church, and I spend the whole day there. . . . When you go there, it is as if you forget everything you're having bad, and you start a new version where it is about God—God who can give you peace, God who can give you good health, God who provides everything because he's a creator. . . . When I suffered, it was not my power, it was not my strength, but God wanted me to survive. Many people died who were having money, who were so strong, but me as a weak person, I was left to remember that God is there. That's why I say to myself that I have to offer two days to spend time with my God. . . . And even the pastors . . . they say there is peace in God, there is love in God, there's everything in God.

In summary, Charity discussed the organizing effects of her Tutsi, woman, and Christian identities; traced the developmental strands of her survivor, disability, and leader identities; and described a tangle of intersecting identities related to family. More specifically, she explained how living through the Rwandan genocide as a Tutsi and losing much of her family gave rise to her identities as a survivor and a woman with psychosocial disability. Several years after the war, when Charity found other people with psychosocial disabilities who wanted to create social change, her survivor and disability identities intersected and generated her leadership identity. As she participated in founding an organization to support people with psychosocial disabilities, her survivor, disability, and woman identities intersected and helped organize her leadership work. She also reported that her Christian identity helped to sustain her as a leader. Finally, Charity described how her identities as a Tutsi, survivor, woman with a psychosocial disability, wife, mother, and Christian wove in and out of one another in a complicated configuration of grief, anxiety, comfort, and love.

**Lizzie.** Lizzie, a disabled woman living in Nairobi Kenya, demonstrated a striking combination of heart and mind during our conversations together. I felt immediately comfortable with Lizzie, and during our time together in the US and Kenya, I appreciated and admired the way that she processed complex understandings of her internal experiences, interpersonal relationships, and wider social context. At the time of our first interview, she was 33 years old, raising two children with her husband, and starting a disability consultancy (This-Ability Consulting, 2017). We conducted our two interviews in English, though Lizzie also speaks Swahili. Over the course of our two in-person interviews and additional conversations together, Lizzie shared how her relationships helped organize her disability identity, which developed in stages and mutually influenced her motherhood identity. She also mentioned a *mélange* of cultural identities, as well as being a woman, wife, entrepreneur, disability consultant, and person of faith.

Lizzie offered some background on her family and myriad cultural identities.

My dad is Kikuyu. My mom is from the coast. She's Giriama. . . . So I am half Kikuyu and half Giriama. . . . I have a [younger] sister and I have two [younger] brothers. . . . Because [my dad] was in and out of our lives, we didn't grow up knowing about the Kikuyu culture or the traditions or even the language. I don't think you'll know a Kikuyu who doesn't know their language; the Kikuyu's are a very dominant tribe. . . . My mom, as much as she is Giriama, she grew up in Mombasa, which is a coastal city, and she also did not know her language, her mother tongue. So we spoke Swahili and English in the house, and the only culture we were exposed to was Swahili culture. And Swahili culture is very laid back. I think it's the same in any coastal town—very friendly, very laid back, not too focused. The Swahili stereotype is that . . . they're not go-getters. They worry too much about what people would think.

Lizzie was aware of tension between her personal drive and her cultural tendency to worry about others' perceptions of her as she earned her undergraduate degree at the United States International University-Africa and started her career and family, but most of all, this tension arose as she developed her disability identity.

Lizzie acquired her disability when she was 19 years old. “I was in an accident . . . It was a car crash . . . and I lost my leg. I was in intensive care for quite a few weeks . . . From intensive care I stayed in hospital for about three months.”

In the earliest stage of Lizzie’s disability identity development, she experienced her disability as a loss, but Lizzie’s mother, who stayed with Lizzie in the hospital, played an important role in organizing a positive shift in the way that Lizzie approached her new changes and challenges. She reminisced,

I don’t think I would have gotten through anything without her. She made the most serious of things seem like fun—not being able to go to the toilet by myself. . . . It was uncomfortable at first, but then she would crack jokes all the time.

Lizzie’s mother intentionally imparted the message that Lizzie’s disability was not a tragedy.

I remember when I found out that I had lost my leg. It was crazy. I was crying, and you know, [my mother] would come into the room and nothing. . . . I never saw her cry . . . and she wouldn’t let me feel sorry for myself [chuckles]. . . . I kept wondering, “Why wouldn’t you cry? I lost my leg. Why wouldn’t you cry?” And she’s like, “No no, no one’s crying here.”

Lizzie reflected on the intersection of her age, disability, and relationship with her mother. She described how losing her sense of independence as an emerging adult felt particularly devastating but reflected how it also strengthened her relationship with her mother.

I was nineteen, and I had just started working. . . . At that age, I think teenagers feel like they want to be independent, and they don’t need their mothers. . . . So it was very interesting that I had my accident then because it really brought us together. I went from not needing her to fully being dependent on her.

Over the coming months, the resolute attitude of Lizzie’s mother, combined with her mother’s affirmation of her choices, supported Lizzie’s disability identity development as she transitioned back to work and into her social life. As she regained her

strength, Lizzie harnessed the determination that her mother modeled for her. “I moved from a wheelchair to a walker, and a walker to two crutches, and then to one crutch. . . I went back to work, went back to dating.” At this stage, Lizzie decided, with some uncertainty, to ignore or cover her disability as best she could, and her mother kept encouraging her to trust herself and her choices.

Maybe the way I went about it was wrong, but I never talked about my disability. Yeah, I used the crutch, yes, but...my mom kept telling me, “Oh, it’s up to you. If you feel like telling someone, tell, but if you don’t, then you don’t.” And for me, I felt like why should the first thing be, “Oh, you know I’m disabled.”

Lizzie’s decisions about how to portray her disability identity worked well for her externally, but internally, she continued to feel troubled and uncertain about being a disabled woman. On the surface, her relationships with her peers seemed unchanged.

I had just started working at one of the biggest banks in Kenya, so I had a salary. . . . All my peers were in school, in college, and I was the one that was bringing in the money, so it was me that they would look for. . . . They’d know “Lizzie will buy the drinks, she’s the one who’s working,” and I would be fine.

Inside, however, Lizzie experienced tension between her disability and her identity as a woman.

I think for women, you know, society puts so much pressure on what you look like, and my disability is very obvious I guess. . . . Yeah, from being perfect, to suddenly having a deformed body, and I can’t walk right; my posture is not right. It was a very, very big thing.

Her reticence to discuss her disability, which was mirrored by the men she dated, prevented Lizzie from developing a sense of connection in some aspects of her social life.

I never felt I could invest myself in anyone. There was never one that I felt totally free with, and part of that may have been on me because I never talked about my accident. And interestingly, I used the crutch, but no one ever brought it up. . . . I guess I felt no one was worthy of getting to know the real me [chuckles], and the real me was my disability.

The next stage of Lizzie’s identity development as a disabled woman transpired in

the context of an important friendship with the man who became her husband.

I had dated a lot, but I never felt I could be open and be who I am with anyone other than my husband. Throughout my dating history, we were always friends. . . . I knew once we started dating, I would end up marrying him. . . . For me, it was important to be with someone that would not make me feel less than. I did not want to be with someone that would make me wish I wasn't disabled. It was important for me to be with someone that put me on a pedestal with my deformity [laughs]. And he does. And he makes me feel like the most beautiful woman, and I feel safe. . . . He's my best friend.

Although Lizzie described feeling comfortable with her lived reality in the context of her marriage, she disclosed that she was still reluctant to fully embrace her disability in public. "I would never have used the term disabled, even to just say it. I never did. . . . I only started using it after I had my daughter. . . . It's interesting how now it's an empowering term."

When Lizzie had her first child, the strong relationship she had with her mother inspired her decisions about the kind of mother she wanted to be.

My mother passed away in 2004, but she was a big influence. I don't think I would've been who I am if not for her. And when I had my daughter, it was like a light switch went off in my head. You know how you take things for granted when it's just you? And suddenly you have this person, and you realize you have to be better. She's looking at me, and I'm her role model; and I wanted to be to her what my mother was to me.

Lizzie's motherhood identity, combined with the ongoing support of her husband, organized the continuing development of her disability identity. Although her body weakened after a traumatic childbirth, Lizzie sought to live more openly with her disability as an example for her daughter.

When I got married, I was not using my crutch . . . [but] I started using it again immediately after having my daughter. I didn't want to use a crutch because it made me feel disabled, you know? I wanted to go back to being one of the crowd. . . . And my husband, God bless him [laughs], I don't know how he puts up with me. Anyway, my husband um [tears up]. He made it ok. He kept saying that, with or without my disability, I cannot blend into the crowd [laughs]. So I

shouldn't fight it, and I should just use my crutch if that is what I need to be able to walk around, instead of being cooped up in the house, and welcome the attention that the crutch gets me. . . . And he would keep one crutch in his car and one crutch in mine . . . so that I would always have one to use. . . . And that basically helped me. Yeah, and then that brought memories of my mother and how strong she was for me and how difficult it must have been for her. . . . And I was like, "I have to be—I have no option—I have to be better for my daughter! She needs, she deserves a strong role model."

As Lizzie's disability identity strengthened, she experienced a shift in her professional identity and turned her focus more toward disability activism. Her husband again supported her: "I would not have done it without him. I probably would have been still cooped up in the house. Yeah, so that got me looking for, seeking out organizations." Lizzie began volunteering for and eventually found employment with DPOs, such as the National Council for Persons with Disabilities (2016), and then saw how she could make a unique contribution to the activism work. "I realized that there was a need for a disability consultant, and I figured, I might as well get out and start something." The charity ethic that Lizzie noticed around her clashed, however, with the no-pity attitude she learned from her mother and her increasingly confident disability identity. She found that, "Most disability organizations, I think they approach disability as [pauses] oh like wanting to help. It's not an empowerment thing, you know. It's more, 'Oh let's help the poor disabled people.'" As Lizzie became increasingly willing to be conspicuous and candid, she sought to resist the charity ethic of disability by starting her disability consultancy.

When you're registering a disability related organization, most of them are non-profit. Why? I don't agree with that. It makes business sense to cater to the disabled. . . . A huge population of our world is disabled or is going to be disabled because of age. . . . Everyone was advising me to register [the consultancy] as a non-profit. But for me, that didn't make any sense, I guess maybe because of my background, but also because non-profits in Kenya have a bad name. . . . It's all about, "Oh, let's get money from donors and then buy wheelchairs . . . and make

as much profit from it and pay ourselves big salaries.” . . . For me, I would rather be upfront and say, “Yeah, I am charging for this service, and it’s a service that you need.”

Lizzie allowed the value that she placed on relationships to guide how she ran her business and how she engaged in disability activism work. Rather than thinking of her consultancy or the disabled people around her as charity cases, Lizzie sought to take a more community-oriented, empowerment approach. “I’ve always been good at creating relationships, and I use that in my work now.” As a disability inclusion professional, she has engaged in a number of projects and programs. She organized Huu’wezo Women & Wheels, a wheelchair rugby program for women and girls with and without disabilities. She served as a consultant for UNDP Kenya’s Business Call to Action, an initiative that encouraged businesses to adopt disability inclusive policies and increase employment and entrepreneurship opportunities for disabled people , and she continued to operate This-Ability Consulting, the organization that she founded, which promotes disability incorporation in the private sector (This-Ability Consulting, 2017).

Lizzie recognized the intersection among her identities as a disabled woman, mother, and entrepreneur. She found that her entrepreneurial spirit complemented her motherhood identity because she could keep “flexible working hours” as she developed her business. She was clearly incredibly busy, however, as I inferred from her multiple projects and middle-of-the night emails.

Lizzie spoke about her identity as a person of faith within a Christian tradition “Yeah, my relationship with God is a big deal; it’s what makes me who I am” and described how her faith helped organize her family relationships and her approach to life’s challenges. Although she declared that she was “not a big church-goer,” Lizzie

described a number of ways in which her faith and relationship with God played a daily role in inspiring her and helping her to persevere in the face of hardship.

My husband and I, that's how we live our life. When we first moved to the area that we live in, neither of us had jobs, but we moved because we loved the area. . . . And we had a new baby . . . and a new baby was coming; but we knew we did not want our baby living in the area we were living in. And I basically just said, "You know what, God made us." There's a verse in the bible that says, ["Look at the birds of the air; they do not sow or reap or store away in barns, and yet your heavenly Father feeds them."] . . . Our maker is the same, and He knows everything. So I basically put Him to test [laughs]. . . . We didn't have money but somehow figured it out, and it wasn't a struggle. And now we look back and, "Do you remember when we moved and we didn't have . . . we only had one sofa. We only had two plates." And now the house is full. . . . It's interesting how, if you just trust in God, and stay positive, and have faith that—what do they say? "He holds you in the palm of his hand."

As we concluded our first interview, Lizzie reflected on the current state of her identity development and spoke about her most salient identities.

For me, what is most important is being a mother and being a mother with a disability . . . and being a wife. . . . That's not very feminist I guess, but that is what I feel is who I am. I'm disabled, and I am a mother and a wife. My disability does not limit me in being the best mother I can and being the best partner to my husband. . . . I guess it's also an age thing because I feel I am comfortable in my own skin, at last [laughs].

In our final interview, I asked her what terms she preferred to describe her disability and activist identities. She gave a one-word and powerful answer: "Lizzie."

In summary, Lizzie described the organizing effects of her cultural background, relationships, faith in God, and life experiences on the development of her family, disability, and activist identities; she also mentioned some intersectional moments that included her age, woman, and professional identities. She alluded to a complex mixture of Kikuyu, Giriama, and Swahili cultural influences within her family growing up, and she particularly emphasized the profound and influential relationship she had with her mother. As a young woman, Lizzie acquired her disability in a car accident and described



how her disability identity developed in stages over time as she interacted with important others in her life. Initially, her desire for autonomy as an emerging adult, combined with the indispensable support from her mother, helped shape her early disability identity during her recovery in the hospital. When Lizzie returned to her life as a professional, single woman, her mother supported the next stage of her disability identity development by encouraging her to trust in her decisions about how to represent herself in the world. Her peers offered some support by following Lizzie's lead and downplaying the significance of her disability. When Lizzie became romantically involved with her husband to be, his complete love and acceptance of her as a disabled woman influenced the strengthening of her disability identity. She spoke about how her faith in God helped organize her relationship with her husband and the challenges they faced together as they started a family. When Lizzie became a mother for the first time, her identities in relation to her husband, mother, and disability converged in a powerful way. She credited this convergence and her burgeoning relationship with her daughter as the motivation for fully embracing a strong identity as a disabled mother and wife. Her entrepreneurial activism work grew out of this stage of her disability identity development, and she started her own business (This-Ability Consulting, 2017) based on her strengths-based understanding of disability.

**Maru.** María Eugenia, or Maru, a woman with a visual disability from Cuenca, Ecuador, had an extraverted disposition and introspective tendencies as a writer and poet. During the time we spent together in the US and Ecuador, I appreciated and admired Maru's open, friendly, and inviting energy, even amid her exhaustingly busy schedule, and I learned a lesson in open-heartedness from her philosophy of interdependence. At

the time of our first interview, Maru was 28 years old, and she was pursuing her master's degree in inclusive education at the University of Azuay, teaching at the Claudio Neira Garzón Special Education Unit at the Institute of the Blind and Deaf of Azuay, tutoring young children in braille out of her home, and volunteering at the Azuay Society of the Blind. We conducted our first interview in the United States with the help of a professional Spanish-English interpreter and our second interview in Spanish at the end of my stay in Cuenca. Over the course of our two in-person interviews and additional conversations together, Maru discussed the organizing effects of her family, woman, disability, Cuencana, collaborative, and agentic identities and described the developmental journey and mutual influences of her education and advocate identities.

Maru placed a dual emphasis on relationships and personal agency, which pervaded much of her story. With regard to relationships, she said, "Roles within my identity and in my life [are important to me]: being a daughter, being within my family, having friends—I like to have a lot of friends." With regard to her sense of agency, she asserted, "What I think is important that you know about me is that I'm a person who doesn't limit herself . . . and that's [something] I've never said, 'No, I won't. I cannot do it.'"

Maru described coming from a family of women where she first learned to value her relationships and individual strength. Throughout her life, she looked to her mother as an example of fortitude. "[My mother] has always supported me and helped me with everything I need. . . . She got divorced, and she brought up three girls on her own. So, she's very, very strong . . . and she is a fighter."

When she was a young child, Maru found that other people's perceptions of her visual disability organized her early educational development. She explained, "Since I was young, I also wanted to go to school with other children . . . [but] my teachers said that, because I had a visual disability, I could not attend a mainstream school." So Maru began to study at home with a teacher.

Some years later, Maru's disability identity, relational focus, and individual strength intersected and gave rise to her advocate identity. She met another person with a visual disability for the first time, and her understanding of what was possible for her life expanded.

When I was about 12, I met another woman who had a visual disability, and she helped me a lot because she became a role model. I saw that she could do things for herself, so then I got motivated. She also helped me by bringing me to the Society of the Blind in our country, and I became involved in everything to do with disability and decided to study special [and inclusive] education. . . . So I believe that it was basically because of this woman, who was an example in my personal life, that I became more involved with and came to know other people with disabilities and the connection that we should have [with one another].

Perhaps inspired by her mother's strength, Maru started advocating within her family when she was a teenager. She explained,

I have low vision, so for me, I can see more easily—outlines and shapes—when there's a lot of light. Since I was little, I wanted my house to be more illuminated. Yeah so my family didn't want that because they said, if there was more light, it would be more expensive. So after pestering them about not doing what I needed . . . they added more light. . . . And after that, I started working to contribute to the cost. . . . So in that way, we could make an easy adaptation, though it cost more.

Maru's developing advocate identity continued to have a mutually influential relationship with her education and disability identities as she expanded her activism to include community and national contexts. She served as the provincial youth delegate to Ecuador's National Federation of the Blind, where she supported the implementation of

youth leadership workshops in her province of Azuay. She gave an example of a project where she expressed her education identity as a teacher.

We did a project with a town here in Azuay, where we were able to be sponsored to pay for basic English classes for people with visual disabilities. So I helped them because, with the little [English] that I know, I taught them how to write in braille. Generally what happens is that people with visual disabilities know how to speak but not . . . to write English in braille. . . . I worked with [the high school kids] directly and helped them a lot . . . currently, English is a requirement to go on to university, and when you finish at the university you have to have a certain level of English.

Although disability had some influential effects on Maru's development, Maru deemphasized its significance, explaining that disability was just one of many important factors in her life. She shared that she has had low vision since her birth, and that "The doctors stated that the probable cause was that my parents are first cousins." Maru used person-first terminology to refer to disability and stressed the importance of her whole personhood. She also described the embodiment of disability—as "just a characteristic, nothing more . . . like being tall." She expanded on her philosophy of disability by saying

I think disability is in the surroundings, the environment and, of course, the fact of having a limitation or a problem in my eyes. It makes it difficult in my country because, for instance, buildings are not accessible, and they have many stairs, and there are no things in braille; the streets have holes. . . . So I think being a woman with a disability is very difficult, but it's because of the environment, because of the difficulties that the environment poses. . . . The ideal, and what we want to achieve, is that the environment be the one that adapts itself. That can't happen overnight; it's a whole process. We're working for that to happen. But unfortunately, until that happens, we are the ones who have to adapt to the environment that is not accessible for us.

In discussing how she has adapted to her environment, Maru drew from her relational focus and sense of agency to articulate a philosophy of help seeking. She explained,

I think sometimes the need for help is penalized, and I think it shouldn't be like that, because I think people with or without disabilities have a need for help at

some point. . . . First, I believe that I try to do as much as I can by myself, but . . . I think if someone shows the goodwill to help you, it's right, it's good, "Thank you!" . . . While that person is helping me, I would tell them that I am very grateful that you're helping me, but next time, I can do it myself. That way, I make a friend. Because if I tell that person, "No thanks, I can do it alone," then essentially I'm saying, "ciao," and I miss an opportunity.

Maru's educational development involved a mutually influential relationship with her disability and woman identities. At the time of our second interview, Maru shared that she was in the first cohort of students to pursue a master's degree in inclusive education at the University of Azuay. She explained that "Ecuador's law says that children with a type of disability have to be included in schools, but the teachers don't have the training; they aren't prepared to include these children." So she and her cohort were "preparing to train other professors from Azuay" and planning to write "a book about all of us" and the "different [teaching] adaptations, for example, for children with visual, auditory, and intellectual disabilities." Maru also highlighted the prominent role that education played in her identity as a woman.

As a woman, I believe it is important—the same as for all women—to develop myself in different ways. So, one of the most important parts at this moment is the educational part, to get my master's. That, for me, is a goal that I identify with a lot, and I am very attached to it.

While Maru pursued her master's degree, she also expressed her education, advocate, and disability identities by working as a teacher. She taught children orientation and mobility skills—how to use a white cane and how to navigate unfamiliar spaces—at the Claudio Neira Garzón Special Education Unit, which is a school in Cuenca for blind and Deaf students. She also held a braille tutoring program out of her home for children who attended mainstream schools.

I think something should be initiated when [children] are young, which is why, at school, we always work with the youngest, helping them become future leaders,

then teaching them to understand all the mechanisms that they have to continue studying and motivating themselves.

Maru's values regarding relationships, individual agency, education, advocacy, and disability began to generate her identity as an emerging leader. She said, "I'm working to become a leader, but I don't see myself as a leader right now." She acknowledged the individual characteristics that moved her toward leadership: "I'm a person who likes to fight [advocate] a lot," and she cited her community as a significant source of her motivation.

One thing that motivates me or helps me overcome the barriers is when I work with and go to the Society of the Blind that I told you about. There, I can see people that really have a great inner strength . . . and I think, talking to them, it's very, very helpful because they really understand you and know what you're going through. . . . In the Society of the Blind, we work with a lot of projects concerning the teaching of rights.

Maru articulated the definition of leadership toward which she aspired, again integrating her individual and collective ideals. She reflected,

I think there's a difference between being a leader and being an authority, for example. So, when you're an authority, or you're authoritative, people follow or work with you because they have to. I think when there's a true leader, people follow him and they work as a team because that person knows how to get to people, how to motivate them. And it's not that people have to follow him, but they want to, and they want to help him achieve his goals.

The value that Maru placed on relationships and community organized her identity as a Cuencana from Ecuador.

Well, being from the country you're from, you're proud to be a part of it, and I feel that way. In a country, there are good things, bad things, of course . . . like in all countries. I know some parts of Ecuador, but in particular, I love Cuenca. I identify a lot with the city, with its traditions. . . . I think that the people here are very kind and friendly. For example, if there is someone foreign, the majority of people are kind. We try to help him or her to feel okay.

Maru's community orientation appeared to be the cornerstone of her religious or spiritual identity as well. She explained,

I'm not very attached to religion in a specific way—not fully or completely—but I do generally identify with a Christian church. I identify with Christians a little. . . . For me, it's important because I can interact with people who believe in or view God, not just as an image but as a way to become a better person. So that is basically what attracts me to the Christian church that I attend.

Finally, all of the salient aspects of identity that Maru discussed—her relational values, individual fortitude, advocacy, education, disability, womanhood, leadership, the Cuencan community, and Christianity—manifested as a value of social justice. She shared her perspective, saying that

I believe that, oftentimes, there is much injustice and much inequality in the societies of our countries. . . . What I hope to achieve is for people with disabilities in my country to get united and work together. . . . I think that we ourselves shouldn't wait for others to do something but should defend and break down barriers of discrimination. Generally, this is what I think, and it helps me to continue to fight.

In summary, Maru offered developmental identity narratives around disability, education, and advocacy and discussed the organizing effects of relationships/community, personal agency, and womanhood. She cited her family and specifically her mother as the origin of her relational, agentic, and woman identities. Even though she has had low vision since birth, Maru's disability and educational identity development began when she encountered an inaccessible elementary school and began to pursue her education from home. When she was twelve years old, Maru met another woman with a visual disability who became her role model, introduced her to the Society of the Blind, and initiated the beginning of Maru's development as an advocate. Maru began to advocate for more light/access in her family home and soon expanded her efforts to include her community and country through the Society of the Blind. Maru's

disability, education, and advocacy identities influenced one another as she pursued her education, taught children with visual disabilities, and advocated for social justice. At the time of our second interview, she conceptualized her disability identity as just another characteristic and was in the process of developing an identity as an emerging leader. Last but not least, Maru spoke of her love of the Cuencan culture and her participation in a Christian church community. All throughout Maru's life journey, she drew from her relational values and sense of agency to enrich her various identities and experiences.

**Nandar.** Nandar, a differently-abled woman from Yangon, Myanmar, emanated a joyful centeredness and sense of wonder during our interactions together. At the time of our first interview, Nandar was 35 years old and working as the executive director at the Myanmar Physically Handicapped Association (2016) and serving as president and founder of the Exponential Growth Organization. We conducted our interviews in person when Nandar visited Eugene, Oregon—first, in 2013 for the WILD Program and, second, in 2015 for a Trainers of Trainers Program that MIUSA organized for WILD alumnae. We spoke English throughout our two interviews, though Nandar also speaks Burmese and Mandarin Chinese. Over the course of our two interviews and conversations together, Nandar reflected on the development of her education, activist, and differently-abled identities and on the importance of her family and family roles.

Nandar proclaimed the importance of family relationships to her and shared how they intersected with her gender identity. She described having a close relationship with her parents, younger brother, and cousins growing up. She attributed her sense of humor to being around a lot of boys in her family, and after she expressed her hope that my dissertation would make her famous, she laughed and said “I’m just kidding! All of my



cousins are boys and I'm the only girl in my generation, so they are always kidding me.”

Nandar gave the medical label of her disability as cerebral palsy—a condition caused by damage to the brain in its early development, which affects movement, muscle tone, or posture (Mayo Clinic, 2017a)—but explained how her family helped to shape her childhood identity as nondisabled.

My family brought me up as a nondisabled person, so they never thought that I was a disabled girl. . . . In my experience, there were a lot of advantages for me to live as a nondisabled person. I could have self-confidence. . . . I could also live independently because they taught me how to live, how to cook, how to wash. My mother was the most important for me because I'm a girl. So they taught me everything, and they never treated me as a disabled girl. They were able to talk to me like “You are not disabled. You can do whatever you like.”

Nandar's self-confidence motivated her strong commitment to education, and she continued to identify as a nondisabled girl as she attended school. “I also went to the regular [mainstream] school. My classmates and all the teachers, they're kind to me.” In school, Nandar worked hard and dreamed of becoming a medical doctor.

At the time, I also wanted to be a medical doctor. . . . When I was in grade 10, I needed to pass the entrance exams to attend the university. That is a very important exam. At the exam, I passed with high marks. [Consequently,] I could apply to the medical school.

As Nandar prepared to apply to medical school, however, Nandar's family referenced her disability in a new way, and Nandar's love of her family and deference to their perspective intersected with and reorganized her educational path.

According to my disability, my parents thought that if I applied to the medical school, I might face a lot of challenges to do in the school. Now, I'm much stronger and able to walk or run or something like that, [but] at the time, I was not strong and I fell down every day. So they worried for me, and they suggested to me, “If you don't mind, please don't choose the medical school. Please choose the other school, and even if you want to be a doctor, you can try harder and harder and you can get the bachelor's, master's, and after that, you can apply for your doctorate.” . . . So I obeyed my parents' suggestion, and I chose the computer engineering. I got the bachelors' degree and I also got the masters' degree.

After leading her to computer engineering, Nandar's educational path brought her to community activism, in which she continued to emphasize education and began to center an interest in disability rights. A supervisor and colleague who worked for the Myanmar Physically Handicapped Association (2016) gave Nandar a job working with children with physical disabilities.

I didn't know about social work, but I only obeyed my supervisor who asked me to do this work. So I started [doing] social work for people with disabilities. At the time, I started my job as a trainer for the computer and also in the language school, teaching English.

Nandar then began to oversee the scholarship selection process for students with disabilities and to collaborate with other DPOs to advocate for more job opportunities for disabled people in government service and other business.

Nandar's newly sparked interest in disability-focused social work also began to organize her educational path, and her family again contributed to the direction she decided to take. Nandar applied for and received a prestigious scholarship, which she used toward pursuing her master's degree in international development studies at Chulalongkorn University in Thailand. She described how her family's perspectives helped to guide her decision to move to Thailand.

Oh I was so happy, and my parents were so proud of me. . . . And they encouraged me, "You should do it, you should do it." But I was worried that I could not do it, I wasn't sure I was able to live alone in a foreign country for a long time. But they encouraged me, "If you can't do, we will stay with you."

So Nandar drew from her disability and social work identities as she pursued her master's degree in Thailand. She chose to write her master's thesis on inclusive education policy for children with disabilities in Myanmar and found that her department was unaccustomed to disability-related scholarship.

Last year, I needed to defend my thesis on education for people with disability, and I had a lot of challenges defining what literature to use about disability issues. . . . My supervisor [academic advisor] was not familiar with the disability issues, but I was lucky to have an understanding supervisor.

In the process of researching inclusive education policies and identifying future directions for policy in Myanmar, Nandar decided to start her own cross-disability DPO. She explained,

My [previous] supervisor's organization is Myanmar Physically Handicapped Association. This is only for the physically disabled people, not for the Deaf or blind. At the time, I didn't want to do only one type of disability. I would like to do for all people with disability. So I founded my new organization, Exponential Growth Organization.

Nandar designed the Exponential Growth Organization to integrate her love of education, activism, and disability. The mission of the Exponential Growth Organization is to focus on supporting people across disability to advocate for their rights and to build skills that contribute to self-sufficiency. As part of her work, Nandar worked to promote more inclusive education in schools and universities, which involved advocating for policy change, raising awareness about disability accommodations, and organizing the training of volunteer sign language interpreters for Deaf children. She also arranged a media campaign to raise public awareness about disabilities and taught children with disabilities how to become youth leaders in their communities. She lobbied parliament to pass a disability rights law in Myanmar, and she worked with organizations such as Save the Children and the United Nations Children's Fund (UNICEF) to encourage them to better include children with disabilities in their programming. In 2014, UNICEF hired Nandar as an education and peace research consultant.

As Nandar's educational and activist journey led her to focus more on disability, her identity changed from that of a nondisabled girl to a differently-abled woman. In both

cases, she appeared to be responding to stigma related to the term/concept of being disabled (refer to chapters V and VI).

For my identity, I never think like I'm a disabled person. I think I'm a differently-abled person. . . . I don't like the disability terminology because in my opinion, I'm an independent woman; I'm well educated; and also I'm so included in international and local communities, so I think I don't have any disability. . . . I cannot write very fast, but I can type. I cannot move very fast, but I can go abroad on my own. . . . So I have different abilities.

Between our first and second interviews, Nandar's family relational identity expanded as she made some important additions to her family. "Before I came to the U.S., I had a boyfriend, but I had no confidence to get married. . . . I am married now, and I'm pregnant now." Nandar described moving in with her husband and starting a new life together. "We have our own apartment. My husband and I are living together, taking care together. He's a very good person, and he loves me a lot. He's fought for me for more than six years."

Nandar expressed the importance of and mutually influential interactions among her marriage, identity as a differently-abled woman, and activism work. When they first got married, Nandar's husband asked her to stay at home and to stop doing social work, at which point, Nandar told him, "I don't want to stay at home, I want to do my job continuously." Although it may have been unconventional, Nandar's husband supported her. "He said, 'I don't want to hurt you at home. If you feel comfortable, you can continue your work. . . . I want to work harder for you.'" So her husband began helping with the cooking and housecleaning, and they both continued their work outside the home. Nandar said with a playful smile in her voice,

He's very happy to help me, especially for clothing. . . . He's fashionable! I'm not. . . . I changed my hair design because of him. He's my personal fashion designer. . . . [With a more serious tone] I'm so happy with his love and help, he understands

me a lot.

Nandar shared that she felt accepted by her husband's family, while still maintaining ties with her family of origin. "His family loves me. . . . His family is big, and a lot of the sisters and brothers all love me. And they understand my disability, and they try to assist me to be comfortable." Although somewhat nontraditional in her culture, Nandar and her husband continued to have a "good relationship" with Nandar's family of origin and visited them regularly. "This seems crazy, but I eat dinner at my birth house together with my husband."

As she prepared to become a mother, Nandar began to integrate the roles of wife and mother into her identity as a differently-abled woman and into her passion for disability rights.

Being a [differently-abled] woman, I have one thing to talk about. We have the right to have a family. . . . We are human, so we have the right to choose our family, to get married, to be parents. . . . My family and my [community] are not very discriminant of disability, but . . . the society thinks that "How can they get a boyfriend?" It's a normal process for women or girls, but . . . the society thinks that it's so strange for girls with disability and women with disability, especially for parenting a child. Why?

In summary, Nandar described the mutually influential development of her family, education, and disability identities, which started in her early childhood, and her activist or social work identity, which emerged in her early adulthood. She began by adopting her family's assertions that she was nondisabled, which organized her education identity and her success in primary and secondary school. As she approached the augmented barriers of college, her parents perceived and encouraged Nandar to consider her disability in a new way. Again, she took their suggestions to heart and pursued computer engineering rather than medicine. Her interests in education, computers, and

disability came together, however, when she began working for the Myanmar Physically Handicapped Association (2016), teaching children with disabilities and advocating for policy change. Thus her identity as a social worker was born. As her activism intersected with her education journey—she pursued a master’s degree in international development studies—she began to think of herself as differently abled rather than nondisabled. Around this same time, she started courting the man who would become her husband. With the advent of her marriage and with a baby on the way, Nandar’s family and support network expanded. Her many family relational identities—daughter, sister, the only girl in her family of origin, wife, beloved member of a large family by marriage, and soon-to be mother—continued to intertwine and interact with her identities as a social worker, educator, and differently-abled woman.

**Atika.** Atika, a disabled woman from Islamabad, Pakistan, spoke in a slow and measured tone, and a wide smile spread across her voice whenever she spoke about her love of cooking and children. At the time of our first interview, she was 39 years old and serving as the founder and senior program officer at the Young Scholar Educational Society (2012). She also worked as a study-abroad-counselor for youth at the British Council, an organization that focuses on cultural relations and education, and identified herself as a woman of the world. We conducted our first interview in person and our second interview via email. We communicated in English, though Atika also speaks Urdu and Spanish. Over the course of our two interviews and conversations together, Atika discussed how her disability identity organized her activist identity, interpersonal style, and connection to her social class. She reflected on womanhood and offered glimpses of how it interacted with her Muslim and disability identities, alluded to her urban and

international sensibilities as particularly salient, and highlighted her interest in education and life-long learning.

Atika named her disability as muscular dystrophy—a genetic condition that causes progressive weakness and loss of muscle mass (Mayo Clinic, 2017b)—but she explained that, four years prior to our first interview, she experienced an accident that brought her disability to the forefront of her identity. The accident resulted in two fractures to her leg and in injury to her back. She explained,

I was a normal person four years back. I was totally a normal person who would drive a car, go anywhere. . . . Everything was right, [But] just in the blink of an eye, I was like this. So I cried a little bit. But then I got settled: “I have to recognize this problem, and I have to get along with it.” . . . After this accident, it totally changed me so much.

The new prominence of Atika’s disability identity reorganized the way that she perceived the world and inspired her to move toward disability activism. Not only did her accident literally change the way she moved through her environment—using a walker around the house and a manual wheelchair “for long purposes like going to the office and going to the market”—but it shifted Atika’s social perspective and the ways she sought community.

I wanted to be in a learning process. Because I was not a disabled before that, I wanted to see everyone. How do they work? How do they interact? How do they live their lives?

Her longing to learn about disability led to a new motivation—“I’m Atika and I have to go forward”—and to the beginning of her activism work/identity. She decided that

I must do something for others so that they don’t cry like me. . . . So besides crying on my life, I started something social, something good for myself and for others as well. . . . Before [the accident], I did nothing, but then I started volunteering for other disableds. I started to help them around. I started to do a little bit within my financial way so that I could be with them. I could ask them about their problems because, you know, being a disabled in Pakistan, it’s really

difficult.

So she continued doing “A lot of volunteering and trying to make international disability a big thing.”

Atika then helped found the Young Scholar Educational Society (2012), which highlighted her value of learning and signaled the next stage of her activist identity development. The mission of her DPO was to promote access to education for people, particularly children with disabilities, living in remote areas in Pakistan. She described offering her time, energy, and resources to her organization. “So we started over there and made a big program with our own money. We had volunteers. My car was usually used in all the things.” She developed educational policies and curricula, consulted on gender-related education projects, and delivered presentations on independent living throughout Pakistan and the United Arab Emirates. She also worked with the United Nations Development Programme (2017) on a women’s protection bill to protect women from violence, including acid violence, which can create disabilities for women.

In addition to organizing her activism work, Atika noticed that her disability identity and community reorganized her interpersonal style and class identity. She explained,

[Before the accident], I was a little bit, you could say, not an easy person to talk to. . . . I had my special group of friends—you know, a type of spoiled brat [laughs], rich brats, sometimes like that. And now I’m totally changed. I’m not the old one anymore. Perhaps the consequences I’ve faced, the circumstances, everything . . . life makes you change. . . I get along easily with anybody because I am friends with everyone.

Atika expressed a strong identification with womanhood and powerful convictions about what it means to be a woman. “‘Woman’ itself is a big word. Women can do anything in the world, right? . . . I’m proud to be a woman.”



Atika outlined how some of her beliefs about womanhood arose from her Muslim faith.

In my religion, you know, our religion gives a lot of support for women. They say different things—that men can do several things, but God has given so much strength to a woman, much more than to a man. Women can do anything they like.

Atika also touched upon the complicated intersection of her identity as a Muslim woman who has lived abroad and who currently lives in the city of Islamabad. For example, she described the Muslim teaching of Purdah—“Purdah means you have to differentiate between men and women”—and shared how Purdah has influenced and been influenced by the multinational culture in Islamabad.

Now people are changing their thoughts a little bit. . . . Due to change in our culture . . . [women are] working with men, side by side. If they are that much talented, why waste their talent? . . . People used to say something in the start, but now, as awareness grows a little bit in our culture, most of the people can easily understand now how the women can work side by side with the men.

She reflected upon how increased opportunities and increased responsibilities can often go together for women.

A woman has so many opportunities that a man doesn't. Women can work. Women can get married, make babies, whatever they want to do. But men can't. At some point, men just fall down, but women don't because Woman is responsible. She has to be responsible for each and every thing. Like in our culture, she is responsible for parents, for brothers, sisters, for family here. And after getting married, she has to take care of her in-laws, then husband, then children, then grandchildren, see? Women are always busy. . . . Now in this time, women are working in Islamabad as well. In our city, they are working. They are having their own houses, their own families, everything.

Atika linked the cultural shifts in Islamabad and the international experiences of her family to the opportunities that she has personally enjoyed as a disabled Muslim woman.

Even at my house, my parents are not orthodox. They say “But do whatever you want to do. Go wherever you want to go.” They don’t say anything, because we have been living abroad, and our thoughts are like this. . . . I am here [in the US] because my parents have faith in me.

Atika expressed pride in her international identity and linked it to her values of curiosity, cultural exchange, and life-long learning. She stated,

Me myself, I am so much interested in other cultures and other people. . . . I have been to several places in the world . . . I used to live in the UK. I studied from Spain—university level . . . so that’s why I just love to learn about cultures and languages.

She demonstrated her love of learning when she spoke about her educational aspirations, which intersected with disability and activism.

It’s my dream now to work on my furthest degrees with special education . . . and disability studies. And to learn sign language, American sign language. I have learnt a lot from MIUSA, and I hope to do a lot for disableds within my reach.

Consistent with her interest in education and disability studies, Atika expressed a fondness and fierce hope around working with disabled and nondisabled youth.

Because you know, youth is going to change our culture so much. Our society is basically dependent on youth. We are now big, and we can’t do anything, but the youth will . . . grow over time, and they will make changes with the passage of time. . . . In the coming days, they will understand and they will try to change our society and the place for disableds. That’s why I work a lot with the youth.

In summary, Atika discussed how her family, Muslim, and urban international identities organized her normal, learner, interpersonal/class, and woman identities; how experiencing an accident organized new disability and activist identities; and how entering the disability community reorganized her interpersonal style and class identity. Specifically, after her accident, Atika developed a suddenly salient disability identity, which, combined with her love of learning, generated an activist identity that progressed through volunteer, community organizer, and educator stages. As she explored disability

community, she also learned how to be a more inclusive friend to everyone. In addition, Atika made cultural and personal observations about the opportunities and responsibilities of being a Muslim woman living in Islamabad. Atika's disability, activist, learner, friendly, and worldly woman identities influenced one another as she founded the Young Scholar Educational Society, worked with youth, and planned for her future education.

**Balkissa.** Balkissa, a Deaf woman from Bamako, Mali, exuded a gentle kindness throughout our interactions together. A Muslim woman of Songhai descent, Balkissa was 32 years old at the time of our first interview. She worked as an instructor at the School for the Deaf in Bamako, served as vice treasurer of the Malian Association of the Deaf, and served as president of the Association of Deaf Women. We conducted our first interview in person with the assistance of an ASL interpreter and a CDI with experience in international sign. During the interviews, I communicated in English and Balkissa in Malian sign. Due to a number of access and technology barriers, our second interview involved two separate parts. We conducted the first half of the second interview over Skype with the help of a CDI and video relay service, and we finished the interview over email with the help of a French-English translator. Over the course of our two interviews together, Balkissa shared about her educational journey and how it intersected with her Deaf identity, her complex relationship with family, and her development as an activist.

Balkissa introduced herself in relation to her country, religion, and family. "Mali is a strong Muslim country. My family is Muslim, and I grew up Muslim."

Balkissa described how she became Deaf as a child and the organizing impact this had on her educational journey and on her relationship to her family.

I was born hearing, and I went to a public school until I was nine years old. At nine years, I became sick with a very serious illness, and this caused my deafness, plus it caused some problems in my throat. I couldn't swallow, so I drooled and had issues with swallowing. At that time, my parents were ashamed of this condition, and they kept me at home. I wasn't allowed to go to school. I wasn't allowed to go outside and play. They refused me to go out shopping or anything with my family. I had to stay at home, in the house, unable to go outside for three years. It was a traumatic time. I cried all the time.

Eventually, Balkissa's grandmother, who lived in a rural community some distance away, invited Balkissa to come live with her, which shifted Balkissa's experiences both of family and of being Deaf. "My grandmother had a different opinion, and she took me outside, and I would go shopping with her. . . . I was allowed to go out . . . finally!"

Balkissa told the story of a serendipitous event that prompted her return to school and the further development of her education identity.

One day, I was sitting in front of the house on the porch, and my grandmother was in the house doing chores or something. This man walked by. I was just sitting there, and he talked to me—said hi, good morning, or something. . . . I couldn't understand him because he was talking, me being Deaf, and he felt kind of offended; he was an elder, and I didn't respond. . . . He started to get his ire up, and my grandmother heard this and came out and said, "Sorry, sorry, she's Deaf. She cannot hear you." And the man said, "Oh, oh she's Deaf. How long has she been not going to school?" My grandmother said, "We don't have a School for the Deaf," And this gentleman said, "Yes, we do have a school for the Deaf." And so he passed this information on to the director of the school, and the next day, the director came out to my grandmother's home and explained to her about the school and having a program for the Deaf. And so, after this conversation . . . I started going to school.

Balkissa described the next stages of her Deaf and education identity development, which unfortunately, were not as positive as she had hoped. Her return to school involved additional communication barriers and feelings of isolation. She explained that

The school focused on what we call the oral method. In the morning we had speech therapy for two hours . . . and then we had classes in the afternoon. But you have to understand that the teachers didn't sign; they just talked all the time, and often times, they turned their backs to us, and they were talking and writing on the board. And we were Deaf students, so we didn't get any education, right? I mean it makes no sense. All the other students in my class could sign, and so they started signing with me. But I didn't understand what they were doing because I hadn't learned any sign. . . . I struggled with that quite a bit, so it was a hard time in school.

After struggling in school for several months, Balkissa returned home, where Balkissa's family and education-related identities intersected in a newly positive way. One of Balkissa's sisters became an important ally in Balkissa's pursuit of education. She recognized that Balkissa needed to learn Malian Sign Language and made a financial sacrifice to hire a private tutor to teach her to sign. Equipped with new knowledge, Balkissa was able to return to school where she completed fifth grade and three years of sixth grade. Confused by Balkissa's repetition of sixth grade, her sister again interceded.

My sister, who is younger than me, had already passed me in school, and she was ready to go on to college. And she complained to the director and said, "My sister is repeating sixth grade, and I've already passed and am ready for college. Why is she still in sixth grade?" [It turned out that] the Deaf school maxes out at sixth grade, and they didn't have any high schools in the area at all for people who are Deaf.

After repeating sixth grade for the third time, Balkissa drew strength from collaboration with her sister and manifested an advocate identity as she pursued her education. With prompting from Balkissa and her sister, the School for the Deaf contacted the Ministry of Education, and they arranged for Balkissa to attend public school for part of the day.

In the mornings, I went to the public school, and I learned. I got information and had classes there. In the afternoon I went to the Deaf school, and I had one on one work with the director there. And that director at the school could sign, and he would work with me with the information that I got from the public school in the mornings.

Unfortunately, however, Balkissa's pursuit of education at the mainstream school didn't last, because "A lot of parents didn't want Deaf students to be with the hearing kids. They were afraid that the hearing kids would become deaf because the Deaf kids would somehow spread deafness to them." So even though Balkissa acknowledged that "It was quite silly," she began to stay at the School for the Deaf full time, and the public school sent over high school curricula for her to study. Balkissa studied with dedication, and was able to participate in a country-wide university entrance exam. "Out of thirteen [Deaf] students [who took the exam], seven passed the test, and I was one of them."

Then began the next stage of Balkissa's educational advocacy. "The director [of the School for the Deaf] contacted the government to request that the seven of us go to school, and the government said, 'We really don't have a program for Deaf students at the university.'" So Balkissa and the other students got together to brainstorm, and they decided to advocate for government funding to go outside the country to get a college education. They identified Benin as a country with a college program for Deaf students and applied to UNICEF for funding so that they could visit the school, traveling by bus.

It took about fifteen days to travel to the school. We got to the school, and we looked around, and we were just really impressed with the program for the Deaf. And all of us were so, so excited. And it cost, they told us how much it would cost. It was going to be two million in our currency, and that translates to about a hundred thousand US dollars for the education that we would receive there. It was quite expensive. . . . So we passed that information on to the government and they said, "Well, maybe we'll pay for one year and that's all." But the program to complete the studies was three years. So we were encouraged by various organizations and the government to find funds from family, from other places, but of course our parents were so poor, they couldn't afford anything. So after all, we decided it really wasn't going to happen.

Coming to terms with the news that she would not be able to attend college due to financial barriers was very difficult but eventually prompted Balkissa's transition from a

primarily student- to teacher-oriented education identity. At first, Balkissa felt “hopeless, unmotivated, frustrated, completely demoralized, depressed.” After a while, however, she came to accept her circumstances. She told herself, “This is life. This is my future. This is what I am going to have,” and she began to apply her passion for education to the task of educating others.

I love education and love children, and education is so important for me. . . . I currently work in a school, and I work with students, and I see them struggling so much. I see their struggle and I just feel, my heart pains for them. . . . It’s a very difficult life, if you can imagine not having access to information in society. And I know that, if I’m able to help them as children, then they will have access to privileges and opportunities that I don’t have as an adult.

Unsurprisingly, Balkissa integrated her love of education into her activism work. In addition to teaching at the School for the Deaf in Bamako, Balkissa became active in the Malian Association of the Deaf—a DPO dedicated to the promotion of employment rights for Deaf people—and the Association of Deaf Women. Through her work, she taught a variety of vocational and independent living skills in order to build the financial capacity of Deaf women, led trainings on reproductive rights, Ebola, and HIV/AIDS, and organized a door-to-door campaign to disseminate information about preventing violence against women and girls with disabilities—a campaign that contributed to a reduction of violence rates in her community.

Balkissa’s activism and education identities generated her identity as a traveler. She maintained her relationship with UNICEF and periodically received funding to travel to other countries, including Ghana, Côte d’Ivoire, Australia, and the United States, to exchange ideas for improving Deaf education and for advancing disability rights. She said,

I very much enjoy traveling, meeting friends and developing friendships in different countries. I love traveling. . . . Before, my parents were so limiting and wouldn't let me go anywhere. Now, I can decide where I want to go.

At the time of our second interview, Balkissa shared about her current relationship with her family with regard to her Deaf identity. She explained,

I have two families, [a home family and a school family]. I am living with my parents. . . I have eight siblings. There are three girls who have left. I'm the fourth, and the others have married or moved out. . . . We all live in one family house, my parents have their own room, and I have a room that I share with four of us. . . . School is going well in the morning, all afternoon . . . all day. . . . I stay at school for many hours, well into the night, because I prefer the communication, the signing. The moment I get home, there's no communication. . . . My parents don't sign, so we need to use spoken, written language. Most of the time I feel very lonely. . . . [Fortunately,] my grandmother [also] lives with me, and we get along well. . . . She knows some sign, and we're able to, you know, kind of communicate.

Finally, Balkissa expressed a particular affinity for dancing and photo journaling, which she enjoys personally and incorporates into her education/activism work. She said,

I just love dancing, okay. I would go dancing all the time. . . . For example, last night at Susan's house, they had put on some music, and I was taking the opportunity to dance the whole night. It was wonderful . . . and I do like video and taking photos myself for remembering, like of my time here, of last night, video and photos of my [WILD] sisters dancing last night. . . . What I keep close to me is these cherished experiences that I record through photographs and video to keep with me, to remind me of these great times. . . . My journal is images and video—photo journaling, I guess you could call it. . . . And I'm excited, you know, to work with these videos and images [professionally]. In Mali, the NGO I mentioned before, they've given me some video material to show to my [WILD] sisters . . . about what's going on in Mali. . . . And here especially I have so many photos and so many images I've collected to bring home and show everyone [in Mali].

In summary, Balkissa presented a montage of identities, depicting how her family had organizing effects on her Deaf, student, and advocacy identities; how the intersection of her Deaf and student identities helped generate her advocacy identity; how her Deaf, advocacy, and teacher identities influenced one another and generated her identity as a



traveler; and how dancing and photo journalism enriched her community connections and professional identity. Education was a particularly prominent, unifying theme throughout her story. She revealed how becoming Deaf, through the lens of her family members' responses, organized her primary school education. At first, her parents kept her out of school because they were ashamed of her deafness. Later, her grandmother and sister helped her advocate to attend the School for the Deaf, to learn Malian Sign Language, and to continue her education beyond what the school had to offer. Balkissa's identity as an advocate was in full swing by the time she and six student colleagues sought funding to attend an accessible college. Although she was never able to attend college and continue her formal education, Balkissa described applying her love of education to her identity as a teacher at the School for the Deaf, to her activism work with Deaf and hearing communities, and to her ongoing quest to continue learning and exchanging ideas as an international traveler. Finally, Balkissa's delight in dancing and photo journaling also intersected with her proud Deaf identity, her love of learning and advocacy, and the values she placed on raising awareness and building Deaf community.

**Bárbara.** Bárbara, a woman with a physical disability from Lima, Peru, spoke in a clear, ringing voice, navigated social media spaces with agility, and seemed to delight in public speaking. At the time of our first interview, Bárbara was 29 years old. She served as president and founder of the DPO La Asociación Luchando Contra Viento y Marea (ASOC De PCD Luchando Contra Viento Y Marea, 2016) and hosted a nationwide disability-focused radio program (Pymes Peru RTV, 2013). We conducted our first interview in person with the help of a professional Spanish-English interpreter and our second interview in Spanish via email. Over the course of our two interviews and

additional conversations together, Bárbara discussed her identity in relation to her disability, family, and sexuality and identified as an Evangelical Christian and leader.

Bárbara held a salient disability identity. She was born with arthrogryposis—a condition involving the contracture of certain joints, which restricts movement in more than one area of the body (Web MD Medical Reference from the National Organization for Rare Disorders, 2011) and used a power wheelchair. Personally, she described thinking about her experience, not as a disability, but “as a blessing and as full of capacities.” In professional contexts, however, she mentioned her preference for person-first language, explaining that

I use the phrases “person with disability” or “woman with disability” because that is how convention and our legal framework indicate it. I do not agree with people who treat us like “special people” or “people with different skills” because we are all different and we have certain and different skills. Before everything else, we are people.

Bárbara gave a brief overview of her family background with emphasis on the relationship with her mother. Her father left Peru when she was five years old, and Bárbara described growing up with her mother. She said, “My mother was the most important factor in my life because, without her, I would not be what I am now.”

Bárbara’s close relationship with her mother intersected in complex ways with Bárbara’s disability, particularly during her adolescence. She explained,

Like any other teenager, I went through a stage where I wanted to do things that I could not do because of my disability. Moreover, my mom has a strong personality, as do I, so, many times I had the feeling that...[becomes tearful] because she had to take care of me at all times . . . doing all the things with which I needed help, such as bathing, changing, etc.—she felt as though she was getting a little weary. She would sometimes say things like “Well, since you were born I haven’t been able to do many things. I have had to sacrifice many things to take care of you.” But we both love each other dearly.

When Bárbara was 20 years old, she converted to Evangelical Christianity, and

her restlessness and adolescent drive to be more autonomous solidified into purpose and social action.

My aunt and uncle . . . taught me about the word of God. Even though I was raised Catholic, that led me to become an Evangelical Christian. I then understood I had a purpose, and from that point on, I started realizing many things, became really interested in disability issues, and started doing everything I'm doing right now.

Bárbara's Christian, family, and disability identities overlapped as she recognized her lack of awareness and cultivated a sense of compassion, which moved her toward taking on more leadership roles.

My sense is that the process began when I realized I didn't know anything about legislation on disability. I think the reason behind that ignorance was the fact that my mother was always there for me—thank God—and as a result I did not give very much thought to it. Later on, I was struck by the reality that she was not going to be around forever, which she also reminded me of. That is when I began to reflect on the existence of many people with disabilities, especially women who had not had the same advantages that I did, and that, as a result, had not been able to develop a high self-esteem, let alone leadership skills. My awareness of this problem grew exponentially when I got involved with the issue through the media.

Bárbara decided to use her gifts of “charisma and the ability to reach out to people” in order to speak out about disability issues. She started by raising her own awareness by attending conferences and forums on disability as part of the audience. She then began to give interviews and speak about her experiences at conferences. “I started by talking a little about the process I went through to accept my disability, which was congenital, and on how I was able to be integrated in the education system and later on in the labor market.” Eventually, she started hosting her own radio program (Pymes Peru RTV, 2013), which focused on disability rights and the inclusion of people with disabilities within Peruvian society. At the time of our second interview, she had also started to direct and facilitate a weekly, live television segment on a digital channel

(Ventura, 2014).

In addition to raising public awareness in the media about people with disabilities—particularly those in marginalized communities in Lima—Bárbara became involved in a number of other projects that incorporated her disability and leadership identities. She reflected, “I would say that the role of my disability is one of ‘the fight.’” As part of “the fight,” Bárbara started to advocate for increased employment opportunities, the development of microcredit projects, and increased access to healthcare for people with disabilities. She also piloted accessible transportation projects, led the formation of the Special Commission on Disability within the Peruvian Congress, and contributed to the creation of a comprehensive national law mandating inclusive education, accessibility, and access to political participation. In 2013, she started her own DPO, La Asociación Luchando Contra Viento y Marea (ASOC De PCD Luchando Contra Viento Y Marea, 2016). She defined the focuses of her organization as including issues pertaining to women with disabilities, disability rights, and improved access/inclusion throughout Peru.

Bárbara also became an advocate for personal assistants in Lima and shared how her advocacy evolved out of her personal experiences. Growing up, her mother was her primary assistant, so when she traveled to the United States for the WILD program and to Japan for a leadership program through the Japan International Cooperation Agency (2018), Bárbara had some of her first experiences working with personal assistants in a professional capacity.

That experience, based on independent living for people with disabilities, served me a lot because . . . I was away, far from my family. . . . I learned [both] to value my mother more and to be more independent than I was. . . . When I returned to my country, it surprised my mom when I decided to hire personal assistants,

because it signified that she would not influence my decisions or be with me all of the time.

Bárbara next tried hiring her niece as a personal assistant but found that it was somewhat of “A grating experience because we both have strong personalities. . . . So we decided not to continue working together and continue functioning only as family members.” At the time of our second interview, Bárbara had settled on two personal assistants, one to assist with the administration of her organization and other advocacy work, and the other to assist with her personal care. Her experiences of learning what worked best to support her own sense of authority and control led Bárbara to identify personal assistants as one of the focuses of her advocacy work. “I have learned to survive and to be a little more tolerant of other people and most of all, how to make it so that public laws, specifically regarding the theme of personal assistants, are implemented in my country to foster the independent life of people with disabilities.”

At the time of our second interview, Bárbara was also beginning a political career because she believed that “Politics is one of the ways to gain the rights of . . . [and] open many spaces for the inclusion of people with disabilities.” She ran for a councilor position in the 2014 elections in the Metropolitan Municipality of Lima and participated as a candidate to the Congress of the Republic of Peru in 2016. “Unfortunately, I didn’t win, but it was a great experience for me!”

Bárbara also described how she viewed herself on a personal level. “I consider myself very feminine, sexy, modern. Also, I have a strong character, but I am also passionate, a little sentimental, and overall, just.”

Finally, Bárbara spoke about sexuality as a vital part of her disability and woman identities, as a topic that was not adequately addressed in her relationship with her mother, and as a focus for her future activism work.

I believe that sexuality is an important part of my identity as a woman and as a person with disability, but it is also important to recognize that [sexuality] is a theme that is very little assimilated by the parents of a person with disability and by society in general. In my case, my mom never touched on those subjects with me, and I never told her when I began, for example, my sexual activity. Now she knows. This next year, I will approach these subjects more [as an activist] so that they are no longer such a taboo. . . . I am just like any other woman, and I share the same rights and the same responsibilities.

In summary, Bárbara broadcasted a developmental medley of identities that mixed and crossfaded with one another. She began her story by relaying how her identity as a person with a disability and her relationship with her mother overlapped throughout her childhood. In her adolescence and early adulthood, her disability identity intersected with her relationship with her mother in a manner that increased her drive for autonomy. When Bárbara converted to Evangelical Christianity as a young adult, her disability identity, family, and Christian identities, infused with her drive for autonomy, organized a new leadership identity, and she began to advocate for disability rights. Her disability identity merged with her leadership identity as she began speaking about disability publicly at conferences, on the radio, and on television. She became a public figure and began to run for political office as part of her advocacy and leadership work. Finally, Bárbara accentuated important interactions between her identity as a feminine, sexy, modern woman and her identities as a person with a disability, leader, and public figure.

**Fatima.** Fatima, a woman with a physical disability from Blantyre, Malawi, had a deep, gravelly voice and an infectious laugh. At the time of our first interview, Fatima was 32 years old. She served as the founder and program coordinator at the Forum for the

Development of Youth with Disability (2013), where she also coached sports and taught children at her organization's learning center. We conducted our first interview in person and our second interview via Skype. We spoke in English, though Fatima also speaks Chichewa. Over the course of our two interviews and additional conversations together, Fatima oriented her disability, family, and leader identities around her experiences with education. She also identified as Catholic and characterized herself as a tough woman who lived her life independently of men.

In describing her family of origin, Fatima referenced her family's relationship with disability and education.

In our family we have four of us. My [eldest] sister, she's working in the ministry of disability, and the second born, she's a teacher. . . . And I'm the third born, and there's my brother who has also a disability. And we have my mother, my father.

Fatima discussed her early disability identity as it pertained to her family relationships and education.

I was born with my disability. . . . When I reached six years so that I could start school, my parents agreed that I should not go to school—not because they were not loving me, not because they didn't want me to get education, but they loved what they had, me. And maybe people may discriminate me; I could have people mock me; a lot of things may happen to me. So my father was teaching us at home . . . me and my brother.

Fatima's first exposure to social advocacy occurred around her school attendance. She explained,

So my father was teaching me up to the level standard five at home. By then, I was thirteen years old, and that's when there was this organization. . . . It is called Leonard Cheshire Homes. That organization came into our country and into my community. . . . They started searching for those children with disability who don't go to school. So I was one of those people to be traced up, me and my brother. So they came into our house, trying to have meetings with my parents, trying to convince them that I should start going to school. There were so many conflicts between my mother, my parents, and the Cheshire Homes. The Cheshire Homes won the fight that I should go to school. . . . But unfortunately the day I

was going—the first day for me to go to school—I had a fracture because I fell down from the wheelchair to the ground. So my father said, “See, I said Fatima should not go to school.” . . . So I stayed another three months at home without going to school.

Once Fatima finally made it to school, she loved it, and it became a central part of her identity.

I was in another world from the world of just being home without using a wheelchair, without going out anywhere, and I started going out to school. . . . All the teachers . . . they were treating me as their own daughter. I didn't receive any discrimination from my teachers, even my fellow classmates. I started making new friends. . . . So I was just like “I'm in amazing other world, starting a new life.”

Fatima began to build friendships and community—a wonderful phenomenon that intersected with her disability and student identities and that she attributed to the effects of social advocacy.

Those volunteers from the Cheshire Homes, they tried to build relationships between me and my fellow students at school. After school . . . those volunteers were mobilizing my fellow neighbors and my fellow children, and they were coming into our house and trying to train us that “Fatima is your friend. You should have fun with her. You should play with her.” After that, I had a lot of friends . . . Those friends of mine were the ones who were coming into my house. “We are looking for Fatima. Let's go to school. Fatima, let's go and have fun. Let's go, Fatima!” . . . And there was this day that I stayed up to 10 pm in the evening without going home just because I was having a lot of fun. So the starting of school made me change my life.

Fatima's socioeconomic situation interacted with her educational identity and influenced the direction of her educational path. Although she was not able to go to college, “because in Malawi it's very hard for a person who is not rich or who doesn't have money to go to college,” Fatima pursued education whenever and wherever she could. “I studied for business administration. . . . I have my diploma in coaching the youth with disabilities.” She also received a certificate for taking a “disability, sexuality, leadership training” course online and attended the Feminist Leadership Movement



Building program in Kenya.

The act of pursuing education intersected with her spirituality and sparked Fatima's motivation to begin engaging with her community as an activist and a leader.

So after attending that [Disability, Sexuality, Leadership Training], it's when I thought God made me to be somebody else. It's when I thought about establishing the organization which I'm heading. . . . And I started mobilizing people, thinking about how to write a constitution, how to write an organization profile. Where can I find the people who can work with me? Where can I find some resources? In 2009, it's when I sat down thinking about that organization, and it is now growing little by little.

Fatima's burgeoning identity as a leader intertwined with her love of education, and she founded the Forum for the Development of Youth with Disability (2013)—a DPO that promoted the human rights of people with disabilities, particularly youth, and organized skill-based programs to support them in realizing their potential. In her role as program coordinator, Fatima designed and facilitated a wide range of programs, including a project to raise HIV/AIDS awareness and a youth-powered arts-based education campaign to reduce disability-related stigma. She also coached adaptive football and netball, taught at the organization's learning center, and led the Public Works program, a project that supported youth with disabilities in participating in volunteer work and thus demonstrating that they could participate fully in their communities.

Fatima's leader identity continuously interacted with her identity as an active woman. In addition to volunteering her time and energy at her DPO—"Everything which I'm doing is unpaid, because we have never found the funding which we can use to run our organization"—she became involved with the Girls Empowerment Network Malawi (2009). Through the Girls Empowerment Network, Fatima engaged in projects that

supported young women returning to school, encouraged women to become self-sufficient as farmers, and trained young women as actors in the Namiyango Arts Theatre.

Fatima expressed a strong identity as an active woman with a disability. She explained,

I don't take my disability as a challenge, but I take my disability as a breakthrough. . . . When I'm saying a breakthrough, [I mean] I'm not shy. When there is a function that a person wants to take part in, I'm there. When there's church services, I'm there. Weddings, I'm there. When there's some meetings at the community, I'm there, and I have a voice to make.

Fatima also discussed her active woman and disability identities in relation to resisting gender-based violence.

To be a woman with a disability in Malawi is so challenging. . . . A lot of girls who have disability, they are abused by men. We have a lot of rape cases in our country. . . . Men take you as a puppet. . . . They just come into your house and ask you, "Fatima, I want you to be my lover or my wife." After three to four months, off they go. And then another man comes . . . After I went through a lot of challenges, I made up a decision that me, as Fatima, I will not have an affair with a Malawian man.

The intersection of Fatima's various identities manifested in her description of herself as a "tough" woman who is not afraid to express herself forcefully and directly. Although she described refusing to take men as lovers, she acknowledged that a lot of her friends are men. "The main reason of my being in friendships with men is that they should not take me as a puppet. They should treat me as a human being." She reported speaking directly to men about abuse, telling them, "Don't abuse a woman who has a disability. She is a friend to you. She has a right." Fatima has also rebuffed potential suitors, saying "If you want to use me, I'm saying no." Fatima shared how the people in her life have criticized her for her blunt style.

They used to say . . . "Fatima, you are tough and you are rough. You are rude."... I say, "It's me, I'm Fatima. I know what to do. I know what not to do, what's

good.” . . . So I take it as it is, to be rough, to be rude. Yeah, to save my life.

Fatima also identified as a Catholic, attributing the strength she holds in her disability, woman, and leader identities to her faith in God and to her relationship with her church.

God makes an important role in my life because I'm a Christian. I'm a Catholic. And a lot of encouragement that makes me to be here in America [at WILD] today is from my parish priests, the bishops, the sisters, those nuns. . . . They came into my house and encouraged me and my brother. They said, “Don't take your disability as a challenge, but take your disability as a stepping stone,” you see? . . . And just because of the love of God, because God didn't create me to be abused. God didn't make me to be like a beggar. No, God made me with a purpose, and He created me to be a leader. I can see that, yeah. . . . So that's why I thank God that, “Wow, you made me come into this world to do something.”

In summary, Fatima mainly presented scenes from her educational journey, showing how other parts of her identity played roles in or emerged from this story. She shared that her family background organized her perspective on disability and education: both she and her brother were born with disabilities, her eldest sister worked for the Ministry of Disability, and her second sister was a teacher. Because of his understanding of systemic and attitudinal barriers faced by children with disabilities, Fatima's father kept her and her brother out of school, teaching them from home. When Fatima was 13, however, volunteers from Leonard Cheshire Disability (2017) advocated for Fatima to go to school, and themes of family, disability, education, friendship, and activism crossed paths in a deeply meaningful way. Fatima loved school and pursued learning opportunities whenever she could, performing her identity as an active woman with a disability. After experiencing a training about disability, sexuality, and leadership, Fatima generated a leadership identity and founded the Forum for the Development of Youth with Disability (2013). Fatima's identity as a “tough” active woman played a part in her

personal and professional advocacy as she spoke out to friends about abuse and made herself visible in the community. Overall, she attributed her strength as a woman leader with a disability to the organizing effects of her Catholic identity and church community.

**Gloria.** Gloria, a physically challenged woman from Chennai City in Tamil Nadu, India, came across as calm and aware and as possessing a deep reserve of focused energy during our interactions together. At the time of our first interview, Gloria was 39 years old and worked as the India office project officer at Cooperazione e Sviluppo (CESVI, 2017). We conducted our first interview in person and our second interview over email. We communicated in English, though Gloria also speaks Tamil. Over the course of our two interviews and additional conversations together, Gloria organized her discussion of her identity as a single woman and leader with a disability around the development of confidence in her personal and professional life. As she outlined the development of her confidence, she discussed the network of her family, education, Christian, and place identities.

Gloria introduced her family, disability, and education/learner identities together as an origin point for her identity development. She explained that, at an early age, she contracted polio—an infectious disease that can invade a person’s brain and spinal cord and result in muscle pain, paralysis, or death (Global Health, 2014)—which resulted in her physical disability.

I have three siblings, two older sisters and a younger brother, and I am the third. I was not born as a person with disability. When I was nine months old, I had this polio attack, and I got this disability after that. My parents actually are quite educated, and they were in good jobs. They were supporting me to a great extent and giving me best education, all these things, along with other siblings. And my siblings and friends, they didn’t discriminate me. I was privileged, I should say. But there’s something which was going on within me, because initially, I had this kind of feeling that I am a person with disability, and I used to underestimate

myself. “There are certain things which I cannot do”; all these things were there in my mind, because we never used to have this kind of accessibility you have [in the US], special education.

Gloria shared a key moment when she made a choice that increased her confidence as a child with a disability and how this choice sparked the beginnings of her leadership identity.

Whenever we used to have these sports—physical education in our school—I was not able to participate. . . . Nobody said that you should not come into the field or you should not take part, but some way I knew that I couldn’t do it. . . . So one day I was sitting in my classroom, and from my classroom, I was just seeing the ground. And I saw my friends playing. They were practicing for sports day. Then I was really interested and curious to know what is happening there, so I just closed my books and went. When I went there, I saw people were practicing . . . And then, somebody was jumping. They were doing this long jump. So my teacher shouted, “Gloria, as soon as they jump there, I think you will be able to see.” When one person jumped, she said, “Why don’t you draw a line?” So, I thought, “Okay, I’m being helpful; she’s giving me some job. I’m doing something.” So I started doing that, whatever she was asking me to do, I did, like measuring. “I cannot jump, but I can measure. I can do something.” I was instructing people, “Okay next you.” . . . And I was trying to act as though I was a leader. So the other students in my class, they started to listen to me and follow my instructions. I was quite happy about this—the first time in my life that was happening. So, from that day I felt that . . . if you want others to notice you, if you want to do something and you want to be a leader, you just step forward, make the effort to do that. And I’ve been doing that throughout—in school, college, in work place, everywhere.

Gloria’s new leadership identity infused her disability identity with more confidence. She explained that “After that incident, I never felt that I was a person with disability. I really was privileged; I was enjoying all benefits and other lifestyle like any other person.”

Gloria’s drive for ongoing education—a value that was also significant to her family—played an important part in Gloria’s personal and professional/leadership identity. “Education is of course important, and my thirst for knowledge is still there.” She earned her Bachelor of Science in botany at Stella Maris College, a Professional

Computer Training Certificate at the National Institute of Information Technology in Chennai, a Master's of Public Administration at Madras University, and her MBA in human resources management from Indira Gandhi University in New Delhi. At the time of our second interview, she was taking a Diploma Course in Food and Nutrition because she thought it would enhance her work with women with disabilities and benefit her personally.

In describing her development as a leader, Gloria traced the career path that she took to arrive at humanitarian work. She shared, "Because my dad was in another bank, he was very interested in me getting into the banking sector, so I used to apply for all the exams, study and write the exams." But every time she passed the exams and advanced to the interview stage of the hiring process, Gloria experienced disability discrimination, never hearing back from the banks about her application. "I told my dad, 'No, this is very unfair.' . . . I was really frustrated, and I said, 'I will not write any more exams.'" Experiencing and witnessing such discrimination moved Gloria to pursue work that would directly benefit her community. "There are too many issues out there in my country. There's a lot of work for social workers to address like corruption, bribery, casteism, discrimination, etc."

Gloria began addressing the injustices in her society and expressing her leadership identity through her work on a wide range of projects and programs. For a while, Gloria led the Hemophilia Federation India (2017) as the regional manager in South India. She got involved in Alliance2015 (2015) and the International Child Labour Conference. After the tsunami struck southern India in December, 2004, Gloria led the development of an integrated post-disaster care program and advocated for the inclusion of people with

disabilities in shelters and medical centers and for school reenrollment for children. At the time of our interviews, she worked with CESVI (2017), an international humanitarian organization dedicated to supporting collaborative community-based projects and programs for underprivileged social groups and poor communities. She supervised the implementation of CESVI's projects in India and worked to develop, implement, and monitor new project ideas. She also piloted a training project around gender equality to empower women and girls and to sensitize men and boys to prevent violence against women. Even after receiving the Malala Award for her work with people with disabilities, Gloria expressed her desire to devote more of her time and energy to the disability community. "Since I am a full time worker, I am not able to give enough time for some programs related to the differently abled. . . . I am trying to give all my personal time (weekends) to manage the above issue."

Gloria also traced the internal path that she took to becoming a woman leader with a disability and to building her professional confidence.

In the past I used to be very soft, and though I like to be with friends, I never used to talk. I used to be a listener; other people used to talk. I would have liked to make a conversation, but I used to be scared of what others would think—what they would think of me or about my point, my views. . . . And I used to have the stage fear, to speak in public. My inner feeling would be, "I want to do it," but that fear of something, that block was there. If I walked up to the stage, people would see me walking. Because I have a problem, I have a disability, I cannot walk straight, so to take those few steps to go onto the stage, I used to feel a little scared—scared that I would trip down, or people might make fun of me. All those things were there. In this world, working women actually learn a lot, and sometimes they're pushed to do certain things whether they like it or not. . . . So then I thought, "Don't bother about others. Okay, don't have eyes behind you. We have eyes in the front. Just keep looking and walk forward. Being a woman with disability if you're very conscious about people around you or what others are saying, you cannot be a good leader.

Gloria experienced an evolution of confidence in her personal life, as well,

particularly around her marital status and identity as a single woman with a disability.

She explained her initial discouragement: “When I felt again in my life that I’m a person with disability is when they took this topic of marriage. In my country, marriage is something very important. The institution of marriage is actually a very formal thing.”

She noticed how her parents interacted with her identities as a woman with a disability and as an unmarried daughter.

My two sisters, they got married off and they were living happily with their children. When it came to me, I saw that difference in my parents. They were actually hesitant to take that step, to go and tell people and ask for a groom. . . . And the kind of efforts which they took for my sisters, I didn’t see that it was happening for me, because probably they felt a little ashamed to ask people, “[We] have a daughter who has got this problem. Can you look for grooms, or can you have my daughter for your son?” Generally, these talks will go on openly. . . . I don’t know, some block was there, because what my parents felt was, “[The groom’s family] should come and ask.” It’s like they are doing [us] a favor. The groom’s family should willingly come, and they should be willing to take me into their family—because it’s not just a man and a woman, not the bride and the groom; it is a family, you and your family. So, they were very clear about it, “If they are willing, it will be better for you. You can live happily.”

For a while, Gloria’s single woman identity was not as salient as her education/learner, professional/leader, and social identities.

So this went on, and I was not bothered. I was too involved with my education and my job, and I was with a lot of friends . . . and enjoying my life, going out, and all these things. I was a busy person. So I didn’t know that this thing was really affecting me internally.

In the midst of her computer training, however, Gloria made a friend who expressed interest in marrying her.

I met a person, okay. He was my classmate. . . . So we were very good friends, and he became so close to me. And he was very helpful, caring, and all these things. I just considered him as my friend only, but he used to come home and mingle with my people, and everybody liked him. So at the end of our course, when we were about to finish that course, that’s when he proposed. So I was a little taken aback. I didn’t know how to react, but I told him, “You have to come and talk to my parents because I’m a very family oriented person.”



Gloria's family was hesitant, however, because they feared the man's mother and sisters would not accept Gloria because "He was the only son" and the only man in the family. Gloria's suitor insisted that he just needed some time to convince his family

because he was just doing this course, and he was not into a job. So he said, "I will get a job. I'll settle, and then I will talk to them." And then my parents said okay. So this went on for a few years, and . . . I didn't know whether this would work out or not.

At a certain point, Gloria's age began to intersect in a dissonant way with her identity as a single woman with a disability.

Age was going, and there's a pressure in the family that you have to do certain things at the right time. So my people started pressurizing me, and they were talking to him saying, "You just let us know whether it's going to happen or not, whether your parents are okay with it. Otherwise . . ." Because there were a lot of proposals for me which were coming at that time . . . but we said no to all of them, since this was a potential thing . . . since he is a known person, we thought this would be better. . . . And then finally [after a few years of continued pressure], he spoke to his people at home, his mom and sisters, but they refused. They didn't agree to it. So he didn't know what to do. . . . He was saying that his mom was sick. She had breast cancer and so he couldn't force things on to her at that point. . . . So we thought it was best to actually leave him free at this time because we cannot force somebody. . . . So we wanted to close the chapter. . . . I was the one who took the decision. . . . He was actually mad at me. He was very angry for me having taken that decision. But I can also blame him because I said, "You are not brave enough to stand for your feelings and what you want in life." Probably he could have spoken to my people and said, "I need some more time, two years or three years. If you can wait, we will definitely work this out." I would have waited.

As Gloria advanced into her 30s, it became harder and harder to imagine finding a groom whom she liked and respected.

After that [situation with my friend], I was so irritated with men. I didn't have much trust in men. It went on for a few years, and I didn't want to get married to anybody . . . because for me, it was like, "Really, somebody who knows us well is not standing up for us." . . . I started getting alliances, proposals again, but not very good ones I would say. They were not interested in me. They were just interested in my money . . . and a lot of fraud cases also—some married men, just bluffing, saying that they were not married . . . three, four cases, fraud cases on

different matters. Like somebody would say, “I’m working. I have a job,” but they would be jobless. . . . So I was very frustrated. . . . I wanted somebody who was genuine, who speaks the truth—that was my main thing—but I couldn’t find anybody like that. . . . So after that, age went up. For us, when a girl becomes quite old, you won’t get proper alliances. No good grooms would come. And especially a person with a disability, they would be the last choice for a groom.

A sense of confidence in herself and in her unmarried life arose through Gloria’s hurt and frustration, and she chose to embrace her identity as a single professional woman with a disability.

So I just told my parents, “Let’s drop the idea. I’m happy being single. I don’t want to lose my freedom.” . . . But my parents are quite worried because they’re also growing old. So they have been talking to me: “Who will be there to take care of you?” because that’s a big problem in India. So I said, “No, I am earning, and I will save some money.” . . . My job is very important to me because it keeps me independent and free from financial burden. . . . At the moment I’m independent. I can live alone. I can take care of myself. . . . Being a single woman is tough especially in my country. . . . Moreover being a woman with disability and being single, [people] feel that we cannot live independently. So every time they keep advising me to get married. But I am very clear in my decision. I do not want to get married just because others insist or talk about me. I will do so if I feel like it and will choose the right time and person.

At the time of our second interview, Gloria’s identity as a single woman with a disability had practically become integrated with her professional/leadership identity, and she addressed the confidence that she developed within these identities. Although she used the terms “disability” and “differently abled” interchangeably, she made a point to describe herself as a “physically challenged woman challenging others.” She went on to share,

I feel proud to be a woman, and especially a woman with disability, because there are a lot of people who actually look upon me for support and learn from me. . . . It is really nice being a motivator to many people and being a leader to many. It’s a great feeling, to be a woman with disability, being able to do all these things, which any abled woman also might not be able to do. There are abled people who are good leaders. I’m not negating that, but being a woman with disability, you need more strength, courage, and guts to try out a lot of risky things in life. It’s a big challenge. . . . When you’re not strong and you feel very inferior about

yourself, you cannot actually face the challenge. So being bold and brave and courageous really helps.

Gloria also discussed how her family and Christian identities organized her life values and how her church was a supportive context for her as a person with a disability.

Being a Christian, I follow the religious values imparted to me by my parents. I am a regular church goer during Sundays. But if I travel it's not possible. India being a Hindu country, majority of the people are Hindus. Christians, Muslims and Sikhs are minorities. Each community follows its own religion sacredly. But in other religions, especially in Hinduism, people are not allowed to enter the Temples with footwear. Hence if I want to go there or take some foreigners inside it becomes a problem. Since I cannot remove my calipers immediately there, I will always have to make other arrangements, like make somebody else take them. This restriction is there throughout the country. At that moment I would really feel glad that I am a Christian, since such restrictions are not there in churches.

Gloria mentioned place as an aspect of her identity that intersected with her disability and love of cross-cultural learning.

I was born and brought up in Chennai city in the State of Tamil Nadu in India. Chennai being the home town for me is always special. It is a happening place. Though the city comes under the South Indian State, we can find people from all over the country who have come here for studies and job. Hence, though the official language here is Tamil, we can see different cultures and language-speaking communities settled here. . . . The views of people are also different, but since it's a city, the views are much forward than the rural area with regard to disability issues. I have always felt comfortable in this city.

Finally, Gloria discussed traveling as important to her education/learner and professional/leader identities.

I love travel, and I find it the most exciting thing in life. Travel widens my perspective. I enjoy visiting new places, meeting new people, learning about the different culture and setup in each place. . . . Whenever someone calls me over phone or I get in touch with them, the first question they ask me is "Where are you now?" instead of asking me "How are you?"

In summary, Gloria mapped the internal and external development of her personal and professional confidence as it pertained to various aspects of her identity. More

specifically, she identified her family, their love and support, and the values they placed on education and Christianity as a starting point for her disability identity and confidence development. She then described a landmark moment in which she allowed her curiosity to guide her to the sports field, where she learned that she could participate in the athletic events by measuring long jump distances for her classmates. This experience led to the beginning of her leader identity. Over time, Gloria developed confidence as a public speaker and a woman leader with a disability by shedding her worries about other people's judgments. She took the lead in making decisions not to work in the banking sector, to pursue humanitarian work instead, and to intentionally claim her life as a single woman. While her professional responsibilities offered her many occasions to travel and to feed her ongoing curiosity and love of learning, she also expressed her appreciation for the diversity and progressive mindset in her home town of Chennai.

**Hen.** Hen, a visually-impaired woman from Chittagong, Bangladesh, presented as soft spoken and, over time, offered me glimpses of her humor and fiery passion during our conversations together. At the time of our first interview, Hen was 32 years old and served as president of the Women with Disability Development Association and finance secretary of the Alliance of Urban DPO's in Chittagong (2012). We conducted our first interview in person and our second interview over Skype, though the Skype recording malfunctioned leaving us without a record of the interview. We communicated in English, though Hen also speaks Bangla, as well as some Hindi and Urdu. Over the course of our two interviews and additional conversations together, Hen discussed the development of her disability identity in relation to her family, education, activism,

gender, Muslim, and national identities. She also shared a strong sense of being loved, which played an important role in her story.

Hen gave me some background about her family, religion, and country. She described being born into a family that included her father, mother, brother, and three sisters. She shared that her brother and two of her sisters were married and that her youngest sister was studying at Chittagong University. Hen and her family identified as Muslim. Hen elaborated to say, “I believe Allah. He’s everything. . . . Muslim is a very sensitive [religion], and we maintain it. And we like it, our religion, our culture.” Hen and I conducted our first interview just after Eid Ul-Fitr—the Muslim celebration marking the end of Ramadan—and Hen spoke of missing her friends and family and wishing that she could have shared a meal with them during the festivities. In general, Hen described some of the food that she particularly enjoyed as part of her culture and shared the expression “Mache bhate Bengali.” Mache means fish and bhate means rice, so a potential translation might be: fish and rice make a Bengali. Overall, Hen spoke about her country with an almost reverent appreciation. “All Bangladesh is green. And there’s a famous ocean, Bay of Bengal. . . . And Chittagong is a very hilly area and very beautiful.”

Hen explained that she acquired her disability under traumatic circumstances. “I was not born visually impaired. When I was in class nine, I was actually injured by a robbery. . . . They shot at me, and then I had blindness. At that time, my age was fourteen years.”

Hen initially experienced blindness as “very difficult and very different.” She described her adjustment.

After blindness, the next two years I was in treatment. . . . For two years, I could not go outside. At that time I thought, “My life is maybe stopping here. I cannot

get opportunities. I cannot go everywhere. I have no independence. . . . Look at my world. Everything is protected. No independence. I'm always crying. What will I do?"

As her family tried to help her adjust, Hen navigated the intersection of family, education, and her difficult and new disability identity. She worried about stigma and felt overwhelmed by the process of adapting to her experience of blindness.

My father and my family are very educated. . . . My father was charting where is a blind school, where is all that. At that time, we lived in a village, and I could go to Dhaka city, where there is one school for the blind. But I was not interested to go there because of the views of people. [Also], at that time, I didn't understand, "What is blindness? How can I do it?" That is why I couldn't adjust.

Fortunately, one of Hen's friends learned of a blind teacher who taught in a nearby inclusive school, and Hen's visually-impaired and education identities were finally able to intersect in a way that felt manageable and fulfilling.

My friend, near his house, the school is an integrated school. He met the teacher, who is his integrated teacher—resource teacher we call it—and he said, "I have a friend, she's newly blind. If you go there . . ." And the teacher came to my home and chatted with my family. And they ask me, "Do you want to study?" I said, "Yes, I want to study." And my family also agreed, "Yes." [The teacher] was also blind . . . and he taught me some braille, just braille, and then I was admitted [to the inclusive school] at intermediate level. . . . I was really happy at that time. My teacher . . . I'm really, really grateful to him.

Hen first began to develop an advocacy identity in the service of pursuing educational access. When she was ready to take her high school certificate exams, Hen found that the examination hall was located at a great distance from her home. Moreover, she explained "People who are blind . . . they have to attend the examination through a writer. So it's a very big challenge. In Bangladesh, [there were] no available writers." Hen's mother committed financial resources to reserving a car to take Hen to the exam, and Hen's teacher was able to provide braille and audiorecorded materials for her; but Hen still needed to advocate for a scribe to write her answers in print. "I met with my

principal, because I needed a writer and writer permission from the board—otherwise, you can't apply for the exam." Hen's principal agreed to help her apply for a writer and advocate for permission. "Then he got permission from the board, and I was going to the final examination." Hen remembered the day when she heard back about her results.

When I passed that graduate level, it was very fun. After the exam, I went to Dhaka for a visit, for a searching opportunity with my father. . . . My teacher went to [get] the results, and he called me: "Oh, you passed! You passed second class!

After proceeding to and finishing college at Ulhaz Mosthafizur Rahaman College, a national university, Hen moved more fully into her advocate identity, which blended with her disability identity. Between 2007 and 2009, she helped to organize the Disability Rights Group, which evolved into the Alliance of Urban DPOs in Chittagong (2012). She described the types of advocacy projects that she pursued as part of this organization.

Bangladesh had a law, and that law's name is Persons with Disability 2001. But it was a charity law, not a rights-based approach. . . . And that's why [we] started a project with the government. . . . We had some successful activities like advocacy with government for education, advocacy with the social welfare department, advocacy with the police department, advocacy with the metropolitan city. And in Chittagong, [after our advocacy efforts], persons with disability have access everywhere. . . . In Chittagong, in Dhaka [for example], the recreation center, nature park, we'll go to there without fee.

Hen's woman, disability, education, and advocate identities all intersected when she founded and became president of the Women with Disability Development Association. This DPO generates awareness about the rights of women with disabilities locally and nationally and works to educate the government on enacting policies and programs that align with the UNCRPD. She shared proudly about the leadership committee and general membership: "All [of us] are women with disability; no men."

In 2008, as she settled into her organizing and activism work, Hen drew upon her education identity. She recognized that she needed to advance her computer skills and

took a course. “I didn’t know how to operate a computer before, but it was my dream. . . . I had to build up my skills with computers.” She also facilitated trainings on social issues and braille literacy, and had a particular passion for educational advocacy focusing on students with disabilities at risk for exclusion in the school system.

Hen had a strong desire to further develop her identity as a professional woman. Initially, all of her organizing and advocacy took place as unpaid volunteer work. “It was my learning and opportunity to go to the grassroots level. I was trying, and I hoped, if I tried, I’d get an opportunity to work.” Hen noticed that more and more nondisabled women were working in Bangladesh: “They’re working everywhere—garments, factories, and schools . . . [and] many women are doing security force.” She, however, encountered many barriers to finding work as a woman with a disability, including family and cultural restrictions. “Women with disabilities have no access anywhere. . . . On one hand, there is no skill to work, and on the other hand, they cannot go out [because of] family bonding, social bonding.” After a lengthy search and advocating for herself, Hen secured a paid position at Nowzuwan (2014), a local Nonprofit Social Development Organization, as a networking and advocacy officer. “My boss was very nice, and he really liked me to work because I am very sincere about the work and very straight forward [laughs].”

The value that Hen placed on her professional identity overlapped with the way that she practiced Islam and expressed her identity as a Muslim woman.

In our country, you know, every woman has to wear the crown [She may be referring to the burqa] but I am not wearing crown. I just wear my three piece [garment]. . . . When I’m wearing crown, I cannot work. I can’t move. It’s very big—full, whole body from head to leg. So it’s not comfortable for me to wear. . . . So always I am wearing three piece, [which is] a big scarf over my whole body. It’s very comfortable, but crown is not comfortable.



Throughout her unpaid and paid activism work, Hen experienced some tension with her family about leaving the house as a professional woman with a disability.

And the “but”: my family was positive to study but not to go outside. . . . I am open, but . . . my family is a restrictive family, very conservative family. So I was fighting with them [chuckles]: “No, I will not [stay] here. I’ll go outside. I have to do something for me and for all, but first priority for me. I have to be independent. Otherwise, how can I live long life?”

Over the next five years, Hen continued to experience tension with her family and culture as she worked for Nowzuwan (2014) and maintained her leadership positions in the Women with Disability Development Association and the Alliance of Urban DPOs in Chittagong. She explained,

In the village, actually, it’s not possible to stay alone. In our culture, women who are not married, they cannot live alone. It’s very risky, and it’s not our culture. So everybody was scandalizing. That’s why my family [said], “No, you can’t go there, and if you want a job, you can do it here [in the home], but not outside.” And at [the same] time, my office pressured me [to continue working]. Still I was working for five years.

Hen named her decision to leave her job as one of the most difficult decisions she has made in her life. She said,

After five years I had to take a big decision. I left the office. . . . It was very difficult for me. . . . I have no job now, no job. . . . Okay, I’m with my family, but a job is not possible for me. It’s our culture. That’s why it is a very difficult decision for me.

At the time of our second interview, Hen was seeking jobs nearer to her home and applying for disability rights trainings internationally to continue informing her activism work.

Hen also experienced some family and cultural dissonance around the topic of marriage. She explained,

Still now, I am single. In Bangladeshi culture, women with disability, they cannot go to marry actually. . . . Some go to marry, but my family doesn't like me to marry because, in our country, [there] is a dowry system. A lot of murders . . . yeah, the dowry and pressure and physical torture. . . . That's why my father, my mother is always afraid. . . . And also, another thing . . . if I go to marry a man and he doesn't like me, actually, they are afraid divorce. After divorce, what will I do? . . . It's very difficult.

I asked what Hen believed and felt about getting married, and she laughed and said, "I'm thinking I'd like it. I don't know. I would get married." In our second interview, we discussed a suitor who had made a proposal of marriage to her and her family, and I listened as Hen tried to sort through a complex tangle of values and aspirations for her life.

The tensions that Hen experienced in her family did not appear to lessen her deep sense of being well loved, and she particularly mentioned the strong women in her life.

Actually, my support is my family—my mother and my elder sister. My mother and my elder sister, they're always supporting me to help make sense. . . . "Why you feel alone? . . . No, you can go. We are with you." My father also, my brother also, but my mother and my elder sister . . . always supporting . . . strong women, yeah. And my grandmother and my aunt, they always support me. . . . And I have another friend. She always supports me. Because, when I cannot go to the outside alone, she comes to my home, and then we both go. . . . And my teacher, he really loves me. I'm really, really grateful to him . . . and my brother, he very much loves me, my brother. And everybody loves me [laughs].

At the end of our first interview, Hen shared with me a song that symbolized the intersection of her woman, disability, education, professional, and beloved identities. She described listening to it during the two years during which she recovered from her gunshot wound and adjusted to her visual disability. "When . . . I could not go around, I [felt] fully alone. On our national TV is one cartoon, its name is 'Meena.' (United Nations Children's Fund, 2017) . . . Its [theme] song is called 'Ami Baba Mayer Boroadorinme'" (United Nations Children's Fund Bangladesh, 2010). She sang the song

in clear, sweet tones, and explained its meaning. “I’m the only daughter of love me my family. This is the meaning, beloved daughter. I’m growing with the love. Don’t keep me indoors.”

In summary, Hen described her development as an educated, visually-impaired, professional woman advocate and the organizing effects of her family, Bengali, and Muslim identities. She described acquiring blindness as a result of a gunshot wound and feeling traumatized, grief-stricken, and isolated during the first two years of adjusting to her visually-impaired identity. The next stage of her disability identity development occurred when she was able to re-access education with the support of her family, a braille teacher, and eventually, an integrated school. Hen’s advocate identity surfaced as she pursued access to the high school certificate exams, and after college, she helped organize the Alliance of Urban DPOs in Chittagong and the Women with Disability Development Association. She then cultivated a professional woman identity and worked for Nowzuwan (2014) for five years. Eventually, the concerns of her family and the salience of Hen’s family relational identity, as well as the social expectations in her culture, influenced her decision to leave her job and stay at home as an unmarried daughter. Hen’s family also had organizing effects on her identity as a strong woman and as beloved by many.

**Maryana.** Maryana, a Deaf woman living in Amman, Jordan, presented as exuberant and direct during our interactions together. At the time of our first and only interview, Maryana was 29 years old, worked as a physical education teacher at the Al-Amal School for the Deaf (Sharjah City for Humanitarian Services, 2016), and served as a volunteer at the I Am a Human Society for Rights of PWD (2016) and the Jordan

Sports Federation for the Handicapped /Jordanian Paralympic Committee (International Paralympic Committee, 2016). Maryana and I conducted our interview in person with the help of professional CDI and ASL interpreters. I communicated in English and Maryana in Jordanian sign; Maryana also speaks Arabic. Over the course of our interview and additional conversations together, Maryana shared about her activist identity development and how it overlapped with her Deaf, teacher, learner, and athlete identities. She also identified as Catholic, observant/discerning, inclusive, and friendly.

Maryana offered background information about her identities as a Catholic and a friendly/social person. She attributed her ability to be open and friendly to the freedoms that her family and faith afforded her in Jordanian society.

I'm a Christian/Catholic, and my family isn't overly controlling. They do allow me some freedom. . . I feel much more free [to be social]. I'll say hello to people. I'm friendly to people when I'm walking around.

Maryana began her developmental story with a description of her younger self as passive but observant, a description that intersected with her learner and Deaf identities.

When I was younger I was a little passive. I didn't have much awareness. I didn't have the skills. I didn't know anything about the laws. I really didn't know anything, so I was just very passive. You know, I was just kind of like all the other Deaf people around me. . . . And all through university, I didn't have any [sign language] interpreters. . . . So it was just like uh, I had no idea. I just kind of nodded at people, and I just tried to do what I was told to do, and that's how I got through my schooling.

Even though she perceived herself as passive, Maryana made a point to raise her awareness.

Shortly before I graduated, they had an assembly or something where people got together and talked about laws and legislation and that type of thing, so that's where I first started to observe and see that they were talking about different topics such as violence against women. . . . And again, I wasn't active in that group, I was more like a volunteer that would stand there and observe.

After Maryana graduated college with her B.A. in sports rehabilitation from the Hashemite University, her observant passive identity began to transition into an observant active identity. The more that she observed about her sociopolitical context, the more she wanted to raise her awareness and get involved in disability rights.

I saw that the US and Jordan were having some kind of a dialogue, and I was observing this . . . and my eyes really became open because . . . Jordan didn't have a disability law at that time. So I saw how progressive America was, and some people in Jordan were starting to try to copy those things. And I watched this process and I thought, "I shouldn't be so passive" and I started to become a little bit more confident and have more confidence in myself. . . . And again, I didn't have interpreters helping me understand what was being spoken. I had to try to just observe it. And I just felt like, you know, this is something I really should know about.

Maryana's observant, Deaf, learner-teacher, activist, and athlete identities all influenced one another. She declared, "Yes, I am a teacher, that's right . . . and I do love learning very much." This love of learning manifested in her curiosity about different cultures. At one point during our interview, Maryana stopped and exclaimed excitedly,

You know, I see this Deaf interpreter [indicating the CDI] . . . and I just want to chat, talk with her! I want to know "what is it like to be a Deaf American, and what is similar about the sign languages?" . . . I want to learn about other cultures and share my culture.

Maryana gave a few examples of how her Deaf, observant, and learner identities helped her spark anger that fueled her identity as a Deaf woman activist. As she started to get involved, she noticed that organizations would tokenize without really including her.

They were kind of holding me up as a model a little bit, like, "Oh, here's a Deaf person," and kind of showing me off as part of their discussions, but I didn't always know what they were even talking about. . . . So I would stand there and smile and nod, and I would think, "Oh, I'm doing good. Oh, I'm getting up on this higher level with people." But really they were just kind of showing me off.

Maryana shared the moment when she decided she was fed up with being tokenized, a story that featured her athlete, Deaf, and woman identities.

There was an Olympics for those with disabilities going on . . . and, I'm an athlete myself, so people were saying, "Hey, you should be involved." . . . So, I went to the disabled Olympics event. I went to observe what was happening, and they were just laying on the flattery: "oh, you're so pretty. You're so wonderful." . . . And I felt they were using me, just like I was used before! . . . And in my mind, I was thinking, "Oh all you care about is how I look on the outside. What about truly knowing who I am as a person on the inside?" You know, they were very friendly to my face, but Deaf people are really tired of that. We've been used as pawns for a long time, and we're skillful at reading the facial expressions. And they would say, "Oh, you're such a beautiful woman. Look at that outfit, and kind of pat pat on the back. And I'm not stupid, you know! . . . And honestly, that really opened my eyes. That's when I really started becoming aware. . . . And I realized, "Oh you know what, I've just been letting people use me and hold me up in this way for too long."

Once Maryana felt confident in recognizing when she was being tokenized, she moved to a new stage of her activist identity development and started expressing herself. A hearing woman who was active in the disability community offered to mentor Maryana and teach her some social skills, but by this point, Maryana was cautious.

So now I was hesitant. Exactly. . . . I kind of had on a smiling front, "Ok, sure, sure." But behind it . . . I was kind of trying to check her out and see what she was all about. And I observed her behavior around me, and you know, she was showing me off, "This is my friend. This is my friend; she's Deaf." . . . And I was being respectful and polite to her, but she wasn't giving me back the same treatment. . . . And finally I had had it! I decided I would just be really direct with her. And I would just let her know directly how I felt. . . . She's always telling people what to do, and she seems to tell the Deaf people, "You do this. You do that." And so when she tried to do that to me, I said, "Nope, no more. No more of that." So that's when I felt like I was starting to become really empowered.

As Maryana got involved and became more active, her experiences of feeling ostracized and othered shaped her teacher and activist identities. She decided, "I'll be inclusive is what I'll do differently! . . . I want everybody to see that everyone is being included equally." In her work as a physical education teacher at the Al-Amal School for the Deaf, Maryana endeavored to increase the participation of Deaf girls in school sports. She also began to volunteer at I Am a Human Society for Rights of PWD (2016), a DPO

that works to facilitate the participation of people with different types of disabilities in all aspects of community life. Maryana utilized her teaching skills to conduct workshops for Deaf women and youth around disability equality, human rights, and women's rights and collaborated with I Am Human Society for Rights of PWD (2016), the Jordan Civil Society Program (FHI 360, 2017), the Jordanian Developmental Society for Deaf Women (Guide to Civil Society Organizations in Jordan, 2009), the Deaf Cultural Center-Jordan (2017), and the Japanese Federation of the Deaf (2012) to facilitate workshops on leadership development. She traveled to Japan in 2011 for a training, which fed her enthusiasm for cultural exchange. Maryana also began to take a leadership role at the Jordan Sports Federation for the Handicapped / Jordanian Paralympic Committee, where she supported sports matches for Deaf individuals, got to know Deaf athletes for who they really were, and encouraged Deaf youth to become athletes. Additionally, Maryana joined the National Center for Human Rights, where she supported the development of a human rights report on people with disabilities as part of Jordan's involvement in the UN's CRPD.

In summary, Maryana traced the development of her activist identity and shared how it intersected with her identities as an observant Deaf woman, life-long learner, teacher, and athlete. She offered background information about herself as a friendly person, just one of the self-descriptions that grew out of her organizing identities of family and Catholicism. She also identified as an athlete, an identity that interacted with her learner-teacher and eventually, with her activist identities. Maryana stated that she began her evolution as an activist from a place of being passive and observant. She described the first shift in her development as an activist as occurring when she realized

how little awareness she had about Jordan's laws and about disability rights. She then began to rely on her curiosity to learn and on her observant nature to continue raising her awareness. Once she became more conscious of the injustices committed around her and toward her, she began to practice expressing herself and taking on more active teaching and advocacy roles. At the time of our interview, Maryana was applying her learner-teacher, athlete, Deaf woman, and activist identities to advocacy work, workshop facilitation, adaptive sports, and cultural exchange, all the while centering her value of inclusivity.

**Mayette.** Marieta, or Mayette as her friends and colleagues call her, is a woman with a physical disability from Butuan City in the Caraga region of the Philippines. She absolutely embodied for me the WILD slogan of being "loud, proud, and passionate." At the time of our first interview, Mayette was 39 years old and worked with the Department of Social Welfare and Development (2017) within the national government of the Philippines. She also served as president of the Butuan Association of Persons with Disability in the Caraga region, as president of the Butuan Chapter of the Women with Disabilities Group, as an auditor at the Katipunan Ng May Kapansanan sa Pilipinas Inc. (KAMPI, 2009), and as a council member at the National Anti-Poverty Commission (2017), representing the persons with disability sector. Mayette and I conducted our first interview in person and our second interview over Facebook Messenger. We communicated in English, though Mayette also speaks Tagalog, Visaya (i.e., one of the Visayan languages), and Chavacano. Over the course of our two interviews and additional conversations together, Mayette shared the development of her leadership identity, which included educational success, her activism, being a woman role model



with a disability, and international travel. She also expressed a strong, present-day identification with being a granddaughter, mother, wife and partner, and Roman Catholic.

Mayette offered background information that involved her family and Catholic upbringing. She shared that she was raised primarily by her grandparents and that her grandmother played a significant role in her life—teaching her to cook, encouraging her in school, and reinforcing Catholic doctrine. Mayette particularly spoke about her relationship with the church and her grandmother.

Since birth I was a Roman Catholic. When we were children, every six pm, we had to pray the rosary. . . . That's why I have memorized all the chaplets that Catholicism has and doing the rosary. And every Sunday, we had to be in church, the whole family. When I was young, [it was] my grandmother and I. . . . Being a Roman Catholic is what I am very proud of. I'm very grateful about how my grandparents raised me up having the values of being obedient and respectful. Down to earth is the plus factor.

Mayette plotted the acquisition of her disability as an origin point of her identity development. She explained that, at an early age, she contracted polio (Global Health, 2014), which resulted in her physical disability.

When I came out from my mother's womb, I was a very normal child, roaming around from one corner to one other corner. When I reached two years old, that's the time that I got sick, and they brought me to the hospital. . . . Day by day, my feet became smaller and smaller.

Mayette's leadership identity originated in an educational context and interacted with her family/granddaughter identity.

During school times, I stayed with my grandparents. My grandmother was the one bringing me from school and also getting me to school. . . . So my grandmother was very happy when it came to March, because March is our summer, and because every time it's summer, at the end of the schooling, we have recognition. For that recognition, all students who have [high] academic performances, they call up stage and put a ribbon. Lifting my own chair is not my asset, but every March, my Lola would go with me up stage and put me some ribbons, because, every year, I was on the top five. Yes, and the other thing is, one of the recognitions that I always received was "most punctual" because I always came

early, and perfect attendance, you know, as I said, is another academic award that I received.

The continuation of Mayette's leadership identity development in college continued to interact with her education identity and to be organized by her belief in God's grace. She attended Father Saturnino Urios University in Butuan City, 13 hours from the place of her family home, "So when I reached college, I didn't know how to speak their dialect. . . . There, I met people—sometimes they were good to me, sometimes they were not. . . ." In addition to these social barriers, Mayette persisted in pursuing her education in the face of physical barriers.

All my classes were on the third and fourth floor. So I can't remember how many times I fell down the stairs. But I said to my mind, "I have to be in the schools for four years only." . . . And with God's grace, I made it. I made it in four years. I graduated [with a] Bachelor of Science in accountancy.

Mayette participated in extracurricular activities, as well. "I was also an officer for the department in the school government."

After college, Mayette began to shift her leadership identity from its curricular and extracurricular focuses to a professional or workplace focus. She sought to use her Bachelor's degree in the banking sector, and when she experienced disability discrimination in the hiring process, she was undeterred. She drew from her Roman Catholic identity and attributed the barriers to God's greater purpose for her.

When I applied in a bank . . . my opponents were all my classmates. And they knew who I was in the school—my scholastic and my extra-scholastic [activities]. . . . They told me, "You know, Mayette, you'll be the one hired because I know you passed the exam, you passed the interview." But unfortunately, when the results came, they were the ones that made the slot. So I said, "Okay, God has a purpose." And I waited for two years [until] I landed this [current] job. . . . So that's the reason why God did not allow me to work in the bank, because he wanted me to work in an office which is responsible for the persons with disability.

When Mayette began to work for the Department of Social Welfare and Development, the focus of her leadership identity shifted from education to disability advocacy and continued to interact strongly with her Roman Catholic identity and faith in God.

So I started in the department as a simple clerk. Then on the following year, they instructed me to have work on field. . . . There on field, I started to organize the group of the senior citizens. . . . This department is the one responsible for all the programs and services for persons with disability, like other sectors, senior citizens, women, children, things like that. . . . Presently, I'm very proud that God gave me the office that I work in now.

“Then here comes KAMPI.” Mayette further expanded her leadership into disability organizing by joining KAMPI, Katipunan Ng May Kapansanan sa Pilipinas Inc., which Mayette translated as the “Organization of People with Disabilities in the Philippines, Incorporated. . . . This organization is well known internationally.”

Mayette's leadership identity continued to develop and strengthen within her organizing and activism roles. She became president of the Butuan Association of Persons with Disability, and president of the Women with Disabilities sector, which was founded to strengthen grassroots women's organizations in the Butuan region. Within her roles, Mayette worked to increase the contributions of women with disabilities in all aspects of decision making and to facilitate the participation of women with disabilities in the activities of non-governmental organizations and of government agencies.

Mayette's leadership and education identities intersected when the founder of KAMPI began to invite Mayette to travel and participate in trainings. Mayette explained with excitement and wonder tingeing her voice,

So when they invited me to my first activity in Manila—Manila is the capital of the Philippines—there I met different kinds of women with disability. And without my knowledge, [the founder of KAMPI] recommended me to [travel to]

Nagoya, Japan. So that was my first exposure outside the Philippines. . . . That happened in 2004. . . . In 2005, she recommended me to attend the second women with disability conference that was held in South Korea. So there again, I met such different women with disability leaders from Asia. . . . KAMPI is a member of the DPI, Disabled People International, so they have this conference in Jakarta, Indonesia. So again, I was one of the delegates. . . . And ASEAN's mechanism on human rights for persons with disability.

In addition to identifying as an education and organizational leader, Mayette described the boldness of her advocacy as an important part of her leadership identity. She explained that, as a woman leader with a disability, she was unafraid to challenge nondisabled and disabled people alike with harsh realities. "Being a person with disability in my area, as well as in my country, everybody can describe me as a woman with big voice who has no fear." In our first interview, she referenced laws by name and number and told stories about educating government officials on the laws. When this strategy didn't get her the "yes answer" that she wanted from nondisabled government officials, she unabashedly laid out the importance of access, saying,

Who knows? Maybe tomorrow, next week, or next month, you'll be part of our group. . . . You should become thankful to me because I'm just preparing [the environment] for you. You will become old. You will [need to] pass on the ramp. Or maybe your wife, your daughter will become pregnant. All of them will [need to] pass on the ramp! And that is accessible. And see that's the thing that I'm asking you, to make all places accessible.

Mayette also challenged disabled people to contribute to their communities, saying,

How can so many persons with disability say, "No, government did not help us?" . . . So I throw back the question to them, "If you say government did not help you, tell me now, what have you done to help the government, as well? What have you contributed in the society, as well? Because if you want that they consider you as partner in nation building, you have also to give and contribute things that can benefit all of the people in the society, not only yourself. It doesn't mean that you will give money financially, but you have to join simple community activities."

Mayette painted a clear picture of herself as a tenacious woman leader with a

disability.

My description [of myself] as a woman with disability is a strong woman with determination. I always face my challenges with no regret, whether it is a positive or negative result, because for me I cannot rewind the earth. If the time will pass, everything will be put into action.

Mayette's leadership, woman, and disability identities also manifested as identities of being a spokesperson and role model.

Being a leader, disability for me is not a hindrance; I consider my disability as my asset. . . . My task now here is to give voice to the voiceless. There are so many people with disability, including women with disability who live in far farm areas. . . . I tell [public speaking audiences] to see me as their model in order for them to reach their goals and objectives in life.

She also defined her disability identity in terms of travel, which was an important part of her professional and education identities: "My disability is a passport to my journey. Because of that, I have been to different countries and have also met different kinds of people."

Mayette used a sturdy, industrial crutch, which she included as important to her disability identity and described with a family metaphor.

By the way, I have to describe my disability. I'm a [woman] using a crutch in my right hand, because it's my disability that from my knee—right knee below—that is small. So I can't walk without my crutch. That's my second husband, I should say. . . . Yeah, that crutch cannot be too far from me.

Being a wife and partner to her other, human husband was also an important piece of Mayette's identity and one that overlapped with her Catholic identity. "When I asked God to give me an angel to guide me always, He gave me my husband who accepted me for being what I am." She described their courtship.

In our relationship, when we were still girlfriend and boyfriend, it took five years because, when he courted me, I was then twenty five years old. I said, "I want to marry at the age of thirty so that some of my siblings have already graduated from their school. Being the eldest, I should help them [financially] because my father

passed away . . . in 2003, so I have to take the responsibilities.” . . . Every Sunday, he went to our house and we went to church, and after that, we went to our organization, the Singles for Christ. So that’s the time that we spent on Sunday together as brothers and sisters, as we called. And for me I don’t spare time going to theaters, or going out, that’s not what I want. I spared my time in churches or in other houses together with my brothers and sisters sharing, praising God. . . . [Now], I’m already eight years happily married.

When I asked Mayette the secret to her happy marriage, she said,

Respect one another. That’s the best secret. Respect one another. It doesn’t mean that because I graduated a four-year course and that my husband graduated two years, I will always be on top, no. That’s not my principle. My husband is my husband. He is a little bit high because he is the foundation of the house. I am only the light of the house. But in the decision making, we have to listen first: “What is your decision? What is your recommendation? What is the solution?” . . . If he has already a big voice, I have to slow down my voice. So what we say, if he is already fire, I’m the water. If my voice is already up, his voice is already down.

Motherhood was another family role/relationship that deeply connected with Mayette’s identity and intersected with disability. She and her husband adopted a baby boy, who had multiple disabilities. She told the story about how she met and adopted her son.

Our social worker brought him to the office. At that time, he was three weeks old. . . . Unfortunately, two hours after [giving birth], his mother passed away, because his mother at that time was only thirteen years old. . . . And the hospital declared him abandoned. So all the abandoned children go to our office, as our office is in charge. . . . Then in the afternoon, the social worker came back to me and said, “Mayette, do you want to adopt this son?” I said, “Yes.” . . . The first time I saw the child, I knew that he had his disability immediately, but my heart says, “I love him so much.” So my husband came to the office, and we talked. Then my husband said, “Yes.” Then without my knowledge, my mother came to the office . . . so, we were already three. Then in a few minutes, my sister came because she works in a computer center, and our office bought some items. She delivered to the office without her knowledge that there’s a baby. So we were already four in the family. So we got the baby, we brought him directly to our house.

Mayette received a great deal of criticism for trying to adopt a son with a disability. The first instance was when she took him to the pediatrician. “So the doctor, when she

undressed my son, she said, ‘Ooh, this is not a good child. You have to return this.’

Immediately, I told her ‘Stop. He is not a toy. I will not return him.’” Even Mayette’s family expressed confusion: “All my family members they asked me the question, ‘Why did you choose this kind of son?’”

Mayette showcased her intersecting mother, disability, spokes-person, and leader identities, as well as the organizing effects of her Catholic faith, on a particularly momentous occasion when she defended her son’s worth. She vividly described the scene, which took place before a judge, attorneys, and social worker in the courtroom during the adoption process.

Here comes the prosecutor. She asks me, “Oh, okay, can you present to this honorable court, where is the son?” And I tell her, “That’s the son,” then she makes a follow up question, “Why is the son wearing eyeglasses?” Then I answer her, “Because he was diagnosed with having a GDD, or a global developmental delay.” And again she makes a following question, she says, “And why is it that you want to adopt that child when in fact he has this disability?” And immediately I answer her, “With your respect, I have no right to choose who will be my son or daughter. It is only the Lord who knows what is best for me. My task now is to give him immediate information for him to be like the other children.” You know what the prosecutor said? She said, “No comment.” And her head bowed down and her tears fell down. Even my lawyer saw that I was so emotional in the witness stand. . . . Because even though my tears fell down, still [my head was] up high and [I] spoke so fast, and even the judge got shocked, because that’s the first time that they had this case, that a couple wanted to adopt a child who has a disability.

Mayette expanded on the organizing effects of her Catholic faith in offering a sense of purpose to her identity as a mother of a child with disabilities.

[Being a mother to my son,] it’s maybe the reason why God gave me my disability, or another way around, the reason why God did not give me a child for three years. Because if he gave me a child, I would not adopt this child anymore, because I’d have already my own. And if I did not adopt this child, who would adopt him and give all the care that he needs? That is a reason why God gave me this responsibility and two open arms, to definitely embrace, to give him all the love and care. That’s what the story is all about.

Mayette's motherhood and educational identities intersected in the face of the financial barriers that arose in caring for her son. She listed just a few of the expenses involved in supporting him: doctor visits to a developmental pediatrician, ophthalmologist, and neuropsychiatrist; eyeglasses; physical therapy; and medicines. She proclaimed, "I don't care if I have so many debts. I had to borrow because it's too expensive, but I said, 'Because of my son, I will do everything.'" Mayette withdrew from her master's program to put the finances toward her son's wellbeing. She explained, "I had thirty units in my Master's of Public Administration and only one subject left, the research, and after that I had to go with my thesis writing. But I stopped because of the therapy of my son." Mayette's husband also withdrew from a nursing program with one year remaining so that he and Mayette could put the money toward their son.

Mayette's identities as mother, leader, woman with a disability, and Catholic influenced one another and defined her sense of purpose.

As a mother to my adopted son, I can say that I was blessed in having our son because he gives us joy and happiness. He is our strength. Because of him, we continue our journey in a life that is full of challenges but meaningful. . . . I know God uses me as His instrument only. He wants me to play things that are in His goodwill and help other people to come out from the shell. . . . I always, always tell them whenever I give a speech, "God created us equally. He gave us all our talents and skills. Let's use these talents and skills to help others also."

In summary, Mayette described how her Catholic identity and family relational identities, particularly those of granddaughter, wife, and mother, organized the trajectory of her woman, disability, education, and leadership identities. Family and Catholicism identities shaped her earliest identification with leadership, which occurred in intersection with education: Mayette worked determinedly to succeed in school and in the student government, sharing her successes with her grandmother and praising God for grace and



strength. Still organized by faith and intersecting with disability, Mayette's leadership identity took on an organizing/activist role after she encountered disability discrimination in the banking sector—discrimination that Mayette interpreted as God's will guiding her toward disability advocacy. Through her identity as a woman leader with a disability, she found opportunities to travel, learn, advocate boldly, and serve as a role model. Finally, Mayette held close to her heart her identities as a wife and as a mother to a child with multiple disabilities. These identities were strongly organized by her family and Catholic values and by her leadership identity as a strong disability advocate.

**Mbalu.** Mbalu, a participant with a physical disability from Freetown, Sierra Leone, demonstrated fearless determination, focused intensity, and a talent for storytelling during our interactions together. A woman of Limba descent, Mbalu was 30 years old at the time of our first interview and served as the founder and national coordinator at Empowerment for Disability and Social Integration (2013). We conducted our first interview in person and our second interview over Skype. We communicated in English, though Mbalu also speaks Krio. Over the course of our interviews and additional conversations together, Mbalu shared about her journeys as a war survivor and determined student, including aspects of her identity as a woman with a disability, activist, direct communicator, and Christian.

Mbalu's survivor and disability identities came into being in 1999, during the 11-year civil war in Sierra Leone (Human Rights Watch, 2017). Rebels of the Revolutionary United Front (RUF) launched an offensive against Freetown, the Sierra Leonean capital where Mbalu lived, and captured it from government troops and from the Economic Community of West African States Monitoring Group (ECOMOG), a Nigerian-led

regional security force. The armed conflict in Freetown resulted in thousands of civilian deaths, systematic mutilation, abductions, and sexual violence, atrocities that had been occurring countrywide throughout the duration of the war (Human Rights Watch, 1999). Mbalu experienced paralysis from a spinal cord injury and eventually started using a power wheelchair. She described the experience of violence that brought about her survivor and disability identities.

I was not born a disabled person. I was at age fourteen or fifteen when the rebels invaded my country and my city. That was the January 6<sup>th</sup> invasion. I was at the back of my house when I was shot in the chest, and the bullet entered through the spine.

The trauma that Mbalu survived continued through her experience of treatment and recovery.

I was taken to a hospital that was very close to my house. There some first aid treatments were given. Then the doctor said, “There’s no way I can do this kind of operation.” And the bullet was lying on the spine, so I was suffering. There was a lot of pain and so on. And the fighting was so severe, bombing everywhere. And at about eleven at night . . . some top officials, government officials came to the hospital, and . . . the doctor said . . . there’s a patient here that we would like you to take to the military hospital because, what’s happened to her, we can’t do anything about it.” By then I was on oxygen, and they agreed to take me. I was taken to the military hospital . . . where there was a battalion in the camp of the ECOMOG. When I got there it was so terrible. . . . There were a lot of dead people on the floor, soldiers from combat. . . . I was lying there close to an hour. . . . The doctor said they should take me to the operation room. . . . When the doctor started he said, “Mbalu, we are going to use what is available because we’ve got a lot of casualties, and we’ll not give you what we don’t have.” . . . So the operation was done without anesthetic, and the bullet was removed. . . . They gave me a drainage tube because I was having internal bleeding. And the doctor was like, “I don’t know what kept you alive, Mbalu. It’s a miracle.”

Mbalu kept the bullet with her as a talisman of her miraculous survival. Over the next nine months, she convalesced at the military hospital, which continued to be a target of RUF attacks until the Lomé peace accords were signed in July of the same year.

Mbalu found the initial stage of developing a disability identity to be extremely

challenging. “I went home [from the hospital], but by that time I couldn’t even sit upright. I was like, “I have to learn everything all over again.” It was so difficult for me.”

She stayed at home with her family for another year.

Mbalu’s identity as a Christian helped organize her identity as a survivor living with a disability.

I think, in the early periods of my disability, [being a Christian] helped me. . . . There was a time I . . . didn’t think I was important, but you being a Christian, everybody is important in the sight of God. You go to church every day, and you think that over again. That was where I started to clear my mind again. I gained my capacity again, the self-confidence that I could make it. There's nothing impossible. There's a possibility to have a miracle, things like that. You begin to take it in, you read your Bible. . . . There was a time I used to say, “If even nobody cares about me, I know God cares.” . . . I actually draw my strength from Christianity.

The next stage of Mbalu’s disability and survivor identities commenced when she began to mentally resist the notion that she might become a burden on her family, whom she loved and who rallied around her after her injury.

I have a lot of sisters. They would all come around my mother. Everybody would be helping; everybody wanted to make me feel good. And something just filled my mind: “What if my mother died? And my sisters, as time went on, got fed up, got tired of all of this. What would happen? What would become of me?” . . . As soon as I had that thought, my mind changed. I started thinking that I should do something on my own. Then I started to be independent. I started doing things that, even though they were, “Oh, let me help you,” I said, “No, I can do it. Let me do it myself.”

At this point, Mbalu’s disability and survivor identities interacted with her family experiences and gave rise to a strong drive for education. She was convinced that going to school was her best path toward increased personal authority and control, but she struggled to persuade her family.

I said, “You know what, I want to go to school.” They’re like, “No, no, no, Mbalu. . . . Going to school will mean you have to be sitting down for almost the rest of the day, and you have back pains and all sorts of things.” I said, “Yes, but

let me try. If I fail, it's not a disgrace." So I was able to convince them to allow me to go to school. It was difficult though, because I constantly remember . . . it was like, "You're going back to school? How are you going to cope? How will people look at you?" And there's this stigmatization, a lot of stigmatization about being a disabled person in my country, but I made up my mind that it's better for me to suffer whatever I have to now and, in the future, be empowered.

So at 18 years old, Mbalu returned to school, and she experienced powerful interactions between her education and disability identities.

The principal accepted me very well, and even my teachers . . . they encouraged me. . . . And it helped me a lot because I didn't have time to pity myself. There was a time I used to think, "Why should this be me? Why?" you know, all those kinds of thoughts. But I had a lot of assignments, homework to do and so on, so I didn't have time to pity myself. And all that I wanted was to pass my exams, do well, and go to the university. So, I did very well that first year.

Mbalu's first experience with advocacy occurred while she was at school. She eventually moved into a boarding home at the school, which was more convenient for her in many ways, but a set of steps outside the dormitory presented a significant environmental barrier. "I had to go down those steps every morning . . . and in the evening hours again. It was a boarding home for girls. We didn't have men, so all of the girls would come around to pull me up." Mbalu contacted Handicap International (n.d.), to ask if they would modify the steps for her. "When they came to the school to modify it, the school authorities said, "No! We're not going to break our steps because of Mbalu." At the end of the schoolyear, the school officials sent Mbalu home with a letter for her family.

When I got home, I gave the letter to my aunt. My aunt said, "Mbalu . . . why are you so troublesome?" I said, "I didn't do anything." She then read this letter. The letter [said] . . . "The [school's boarding] home is not for people with disability, so if you want to be in a home, go to the Cheshire Home. We don't want you here" because they didn't want to break their steps.

Mbalu was disappointed and might have paused her advocacy identity

development but for the support of an ally. The head of the All Girl Association at the school came to visit Mbalu and offered to take up her cause. “She said, ‘Thank you very much, Mbalu, because you've given me at least the strength to fight for you.’” Mbalu’s ally attended several meetings of the board of trustees. Mbalu continued the story.

The woman said [referring to my injury during the war], “[What] if what happened to Mbalu happened to any of us? She was in a house when this thing happened! If it were your children, would you like somebody to drag them out of school because they're disabled?” Anyway, at the end of the day, Handicap International came and flattened the steps. Ramps are there as I'm talking right now.

Mbalu decided that she wanted to continue her education even though she left high school with very mixed feelings about her educational experience.

After everything that happened, I succeeded, but my mind psychologically . . . I was having this problem. . . “These people, they don't want me here.” . . . In fact . . . I was afraid to tell people that, “You know what, I want to go to the University of Sierra Leone. I want to go to the Fourah Bay College (laughs).” When I first discussed that with my aunt, she said, “Are you crazy? Have you not been there? Don't you know what it takes? . . . So what I did, I applied without telling people. . . . When I got my acceptance I waited a few days [prior] to the deadlines before letting people know. So [my relatives] were like, “You know what, let us just pay for her, so at the end of the day, she will not have nobody to blame. Let her go. Let her see if she can come out of it.”

Mbalu’s college experience also tempered her disability and education identities in the fires of adversity. “I'm the first female with a wheelchair to go to that university because of the barriers—so many barriers.” Due to financial concerns, she chose her courses based on what materials she could borrow from other students, and once again, she struggled with an inaccessible environment.

The university is a very hilly place. . . . There's nothing like ramps there. At times I had to be taking classes in third, fourth floor buildings. So it was like hell for me. I never had an opportunity to visit a library. . . . I took a lot of risk going up and down those steps with my [wheel]chair. . . . Sometimes it used to be very, very frustrating for me.

Mbalu continued developing her advocacy identity in college. She struggled to make it to class because she depended on “strong men with muscle” to carry her up and down the stairs, but her friends were not always available. So Mbalu worked hard to change the location of her classes to the ground level and described the first situation in which she spoke out to one of her professors.

I asked her, “Have you ever seen a ramp on campus?” She said no. I said, “Have you ever seen somebody that has gone so far in her education without her having the opportunity to visit a library?” She said no. I said, “Are those things going to change for the next exams? . . . And if everything is going to stay the way as it is, how am I going to improve? How? I have to be going up to a third floor building, and it's not going to change.” . . . She almost burst into tears. . . . So she moved the class from the third floor of the building onto the ground floor. . . . That was the first day I did well.

By her final year in college, Mbalu had advocated for all of her classes to be on the ground floor, and without having to expend as much energy around access, she noticed a significant improvement in her grades. Mbalu graduated with a double degree in peace and conflict studies and in political science and history from the Fourah Bay College. She had a colorful and eventful graduation story, which I share in Chapter VI.

Mbalu’s disability advocate identity blossomed after graduation, and she continued to integrate education into her activism work. “Since I was in college, I started putting things together . . . ‘Let me establish at least an organization that will cause others to benefit from what I suffered.’” Thus she founded Empowerment for Disability and Social Integration (2013), a DPO dedicated to promoting the integration of people with disabilities into society across Sierra Leone, irrespective of their tribe or region, and to advocating for access to education, equal rights, and leadership opportunities. Within her role of national coordinator, Mbalu formed partnerships with other organizations and stakeholders involved in disability issues, raised funds to support the organization’s

programs, and conducted community outreach activities. “Basically as of now, I'm concentrating on educating people [with and without disabilities] about disability rights.” Mbalu also joined her organization to the Sierra Leone Union on Disability Issues, an umbrella organization that represents disability organizations in Sierra Leone.

Between our first and second interviews, Mbalu returned to her alma mater to make some changes. “[At] the university, I was given an office space. I was able to advocate for disabled students to be given the government grants . . . [and] we were able to construct the first ramp in the university.”

During the devastating Ebola outbreak in 2014-2015, Mbalu expanded her education and activism work to include a focus on health.

I [volunteered] with other organizations that were working on health. So when they had their sensitization, we went to, for example, disabled homes, to teach people what to do, not to shake hands with people, no body contact, wash your hands all of the time, things like that, to help prevent Ebola.

In our second interview, Mbalu reflected on the current state of her identity as a woman activist with a disability.

As of now, I just think that there's nothing wrong with me. I just can't use my legs. . . . As a woman with disability . . . that has made me somebody special. . . . Before now, I used to think this way that we are just victims of circumstances, and everybody is ignoring us. We've suffered from so much. . . . All of those kinds of things were in my head, in my mind, all of the time. So because of that, it's easy to get angry at people. You're not pleased with anything. You become frustrated. But as time goes on, I begin to realize certain things. . . . If I were not disabled, I would not be in a position to negotiate for other people.

Mbalu also spoke to the current state of her identity as a survivor in our final interview.

I think the fact that I could survive a bullet from the chest to the spine has made me somebody different. I used to tell my sisters that the things that killed thousands of soldiers have only made me stronger. . . . Sometimes I'll just look at [the bullet], I'll play with it. I'll think if this bullet did not kill me, if this bullet did

not bring me down, then nothing else will bring me down. If I survived you, I can survive Ebola. I can survive anything.

In summary, Mbalu discussed the development of her survivor, disability, education, and activist identities and some of the organizing effects of her Christian and family relational identities. Specifically, she described how she acquired her disability by surviving a gunshot wound during the 11-year civil war and how she drew upon her Christian faith and identity to help her organize her disability and survivor identities according to a miracle rather than a victim framework. After her long stay in the hospital and about a year at home with her family, Mbalu decided that she wanted to infuse her survivor, disability, and family relational identities with increased personal control. She decided that fulfilling more personal care tasks herself and pursuing education would be the best avenues toward personal empowerment. In high school, Mbalu learned about persistent advocacy by observing how a woman from the All Girl Association supported the need for a ramp at Mbalu's dormitory. Mbalu began to identify as an activist in college. She drew upon the student community for assistance and asserted her right to attend her classes in accessible spaces. After college, Mbalu started her DPO, which involved the continuing development and interaction of her survivor, disability, education, and activist identities. She advocated for and educated others about disability rights and the individual effects of living through war, and witnessing the positive impact of her work further strengthened her disability identity. Finally, when the Ebola outbreak occurred in 2014, Mbalu continued educating and advocating and drew once again on her miracle/survivor identity to give her courage.

**Melba.** Melba, a woman with a disability of physical origin from Tijuana, Mexico, left me with an impression of humility, maternal kindness, and a calm strength.



At the time of our first interview, Melba was 34 years old. She had recently earned her master's degree in communication sciences at La Universidad Autónoma in Baja California and received a promotion to general director of the national program on the rights of persons with disabilities at the National Human Rights Commission (La Comisión Nacional de Derechos Humanos México, 2016). Melba and I conducted our first interview in person with the help of a professional Spanish-English interpreter and our second interview in Spanish over Skype (with a bilingual colleague present, just in case). Over the course of our interviews and additional conversations together, Melba shared aspects of her development as an activist and as a spiritual being, which she intermingled with pieces of her identity as a family member, woman with a disability, hard worker, and Mexicana.

Melba started her story with her family of origin and alluded to the ways that her family organized the beginnings of her disability and activist identities.

I have a big family. I am the oldest of five siblings. And we all did many things at home, so the relationship between us was equitable. And I think inclusion begins in the family. And growing up with this confidence, with your family loving you no matter what you do or don't do, this helps you to build relationships with other people in society in the same way. . . . I believe that everything in my life began with having two aware parents who always insisted on telling me a very powerful phrase, which is, "Yes, you can." And whenever I said, "No. I can't, that's craziness. I'm not going to be able to do it," they would tell me, "Yes, you can." And so then I would try many times to see if I could do it.

She also described the beginnings of her spiritual journey.

I spent eleven years of my life—preschool, primary school, and secondary school—in Catholic school. I attended more than twelve spiritual retreats, Catholic spiritual retreats, but at that time it was more a learning phase than a conviction. And when I was at the university, then I started learning about other religions and visiting other temples. . . . And it was after that that I connected with my spiritual side. And the more I feel connected to God, the more I feel that my life flows. And I always remember words that my grandmother used to say. She

always used to say, “Always trust God,” and when I do that, it feels like the load on my shoulder becomes half as heavy.

Melba discussed the origins of her disability. She identified as having rheumatoid arthritis—a chronic disease that causes joint pain, stiffness, swelling and decreased movement of the joints (Murphy, 2017)—which began when she was two years old, and which took some time to diagnose.

When I was very young, they did not know that I had arthritis yet. It took a delay of three years for them to know. So I would say, “I can’t walk. I can’t because my legs hurt,” but they didn’t see it. . . . I was [eventually] diagnosed with childhood arthritis at five years old.

Melba shared her conceptualization of disability as an adult and the language she used to discuss her disability identity.

I say, “I am a woman with a disability of physical origin” because one of the things that we manage as part of disability is how it results from the combination of physical deficiencies . . . and the barriers from the environment. So, for this reason, I say that I am a woman with a disability of a physical origin, because the majority of the deficiencies that I have are physical, but the barriers that I encounter can also be [for example] from attitude.

The confidence that Melba’s family instilled in her began to manifest as an activist identity when she discovered community service.

When I was twelve, in the private [Catholic] school that I attended, the principal invited us to put together a group of people that helped other people in the community. . . . And I felt great about helping others.

Melba remained involved in community service through high school, and eventually became the president of the club.

Melba told a story about a particularly meaningful project that increased her confidence in her leadership skills and launched her fully into her activist career.

During my last year of high school, we were asked to put together a project to help the community. . . . So what I did was to put together a Christmas party for families of people with disabilities, and I managed for [all] the eighteen people in

my class to participate in the project. . . . What we did between us was to bake cakes, make different kinds of food, and put together different kinds of sweets and things we could give them. It was so much fun! And we found sponsorship to give presents to a hundred kids. We went business by business, door by door, asking for . . . [donations of] two, three, four, presents. . . . When we did this party, I managed to find a Santa Claus costume . . . for a friend of mine. So when he was dressed up and about to give the presents to everyone, he came up to me and said, “I can’t do it. I can’t do it because I’m very nervous, and I don’t know how you managed to convince us all to participate in this project.” And he said, “The project’s very good but I don’t have the character to relate to kids.” But I talked to him for five minutes, and he was then in the middle of the room talking to the children giving them presents. We were giving everybody a piece of cake; then I turned around, and I saw Santa Claus sitting in the middle of the room next to a girl with a walker, who had cerebral palsy and had many involuntary movements, and who was smiling and yelling out of emotion, out of excitement. So I felt the whole room was paralyzed, and in that moment I felt that I was doing what was right. . . . And from then on, I became involved in disability issues.

Over the course of her adulthood, Melba continued to evolve as a woman activist for disability rights, an identity that drew from her family background and disability identity. Out of high school, she became a volunteer for an association for children with disabilities. “My job every year was to put together that same [Christmas] party for several years in a row but also to talk to parents with children with disabilities to have confidence in their kids, [and] to build their kids’ confidence.” Over the course of her career, Melba held advocacy and training roles within the Mexican government and the Arthritis Foundation of San Diego (2017), which organized summer camps for youth with rheumatic-related disabilities. She then began work at the National Human Rights Commission (La Comisión Nacional de Derechos Humanos México, 2016)—an organization that investigates potential human rights violations and works to promote programs that ensure Mexico’s observation of human rights treaties and agreements—where she became the general director of the national program on the rights of persons with disability. As part of her work, Melba organized and facilitated trainings and

workshops on disability rights for teachers, government employees, students, and community members. She particularly focused on advancing the rights of women and girls with disabilities by urging the government and private companies to hire women with disabilities and by directly encouraging families of girls with disabilities to hold high expectations and to foster an understanding of women's and disability rights.

Melba attributed her success as a disability rights advocate to her own experience as a woman with a disability. "The project of my life and work is guided by being a woman with a disability. . . . Without having a disability and without accepting it as a reality, it would seriously be very difficult to be involved in this work."

Melba identified as a hard worker at school and in her career, an identity that originated with her family and intersected with her identity as a woman activist with a disability.

When I would go to school, my parents would always say, "You have to make a little bit more effort than the others so that your teachers understand the importance of giving you an education too." And they would tell me, "If you make the effort, then they will make the effort because you are being an example."

This strategy of putting in extra effort, which I discuss in greater detail in Chapter VI, continued throughout Melba's activism career.

When you have a disability in Mexico, you have to work two or three times as hard and prove yourself two or three times as much as people who do not have a disability to show that you can do the job. But if you're a woman [with a disability], you have to prove yourself four or five times as much. . . . I am accustomed to working a lot, but when you are done with traveling and arrive tired from the flight, you immediately begin working and start to work, work, work. There is no time to rest your body. For example, I have arthritis. I live with pain twenty-four hours a day, seven days a week, but there are only certain moments permitted to me in which I can have a rest.

Melba's spiritual identity organized and interacted with her identity as a woman activist for disability rights. She explained.

My spiritual relationship, spiritual things, always strengthen me the most. I am Catholic, but I am not orthodox Catholic. Sometimes, I go to Mass; sometimes, I meditate; sometimes, I go to nature; sometimes, I have someone read the color of my aura and how I feel energetically; and sometimes, I speak to a friend who is a priest. Most of all, I do meditation, visual meditations that strengthen the spiritual part—the understanding that we are spiritual beings living a human experience, like I am not this body, I am not this job, I am not a woman fighting for social rights. I am something more than all of these things. Those are characteristics or an experience that I am having right now. . . . Feeling my spiritual being, it is the way that I face many challenges. . . . And learning to treat the other person how you deserve to be treated yourself. That's another one of the tools of and for doing my job.

Melba also strongly identified as a Mexican woman or Mexicana.

Being Mexican is also something that I feel very proud about. When I went this past September to the UN, I tried on a blouse made by indigenous people of Oaxaca, which is one of the states in the south, and many people told me to buy new clothing, a brand name handbag, etc. And I said, "No, I am very happy to be a Mexican woman, and I would like to demonstrate this everywhere, especially at an international conference." So I put on my blouse, made by indigenous Mexican hands from a city in Oaxaca in a pink color. It's a strong pink, a Mexican pink. And so I believe that this blouse defines a lot of what I feel. It is a blouse with a strong color, with a pink color that is identified with femininity, and embroidered with Mexican embroidery, so it characterizes an element of my identity. I value other cultures, but I am so proud to be Mexican. My favorite food is Mexican food. My favorite music is Mexican music. My favorite country is Mexico and the different spaces it encompasses.

In summary, Melba shared the development and interactions of her woman, disability, activist, hard worker, and spiritual identities and the organizing effects of her family and Mexicana identities. More specifically, Melba traced her journey of becoming a disability and human rights activist back to her family. The confidence and inclusion that she experienced in her family and the encouragement they provided motivated her to work hard to include and support others. In school, she also learned about the Catholic religion, which established her spiritual foundation and which helped move her toward

engaging in community service. When she was a senior in high school, Melba organized a Christmas party that was particularly meaningful to her: she rounded up volunteers, organized the event, raised funds, encouraged a classmate to stretch himself to play Santa Claus, and witnessed a moment of sheer joy in a young girl with a disability. This moment brought together her hard work, her leadership skills, her family and Catholic values, and her identity as a woman with a disability and solidified a career dedicated to disability and human rights. In college, Melba expanded her Catholic identity to a broader, spiritual identity, which emphasized diversity and human dignity and which continued to organize her activism work. Her strong identity as a woman with a disability of physical origin also guided Melba's activism work, particularly her work with women and girls with disabilities. Finally, Melba shared the love she felt for her country and her pride in being Mexicana.

**Nathalie.** Nathalie, a physically handicapped woman from Ouagadougou, Burkina Faso, spoke her truth in a quiet but firm manner and emanated a gentle warmth during our interactions together. At the time of our first interview, Nathalie was 35 years old and worked as a sociolegal advisor at Handicap Solidaire Burkina (2017), where she managed a drop-in center and the Espace Bambino Children's Center. She also volunteered at a number of organizations with an emphasis on disability rights and development for children and families (e.g., International Service, 2016; Lasting Action for Inclusion Burkina, 2014, 2017; Light for the World, 2017). Nathalie spoke French, Mòoré, and English. Although Nathalie is fluent in written English and in her comprehension of spoken English, she explained that she was uncomfortable with English pronunciation and asked if we could conduct our interview in French. Therefore,

Nathalie and I conducted our first interview in person with the interpretation help of my French- and English-speaking neighbor and our second interview by email with the help of a French translator. Over the course of our interviews and additional conversations together, Nathalie revealed a tapestry of identities that involved relating to her family, being an educated, Burkinabe, Mossi, handicapped woman activist, and having a Catholic faith.

Nathalie provided some background information about her family as an origin point for her multiple identities.

I come from a big African family of nine children. I have five sisters and three brothers. . . . I lost my father in 1998. My mother is a housewife with no income. . . . I [currently] live with my mom, my three brothers, and two of my sisters.

Nathalie wove together her handicapped identity, her relationships with family members, and her education identity in her story.

When I was four, I contracted polio (Global Health, 2014), and as a result, I was paralyzed in my lower legs. And my father, after that, he didn't like me anymore and discriminated against me after the illness. . . . [He] rejected my mother when he found out that I was disabled . . . [but] my mother always says [to me], "You can do this. You can do that. You can do it." and it really has helped me to have confidence in myself. . . . [My father] did not want me to go to school because of my disability. . . . So my uncle supported me in my schooling all the way through college. And it was after that when my father saw that I could do well, that he again supported me. . . . I am the only one in my family with a disability . . . and I'm the only one who has a college degree.

When I asked Nathalie what term or identity label she currently used to describe her disability, she replied: "I use the term 'handicapped person' or 'person in a situation of handicap.'" The term *handicap* is a direct translation of the currently preferred disability terminology in French. Nathalie went on to express her identity: "To describe me, I love the phrase 'Nathalie, a handicapped girl, proud and fighting.'"

Nathalie's description of herself emphasized her education, activist, woman, and handicapped identities as mutually influential. "I had the chance to be educated and to have a brilliant career." She earned her bachelor's degree in law, which she used every day in her position as a sociolegal advisor at Handicap Solidaire Burkina (2017), a DPO that (a) works to educate and empower people in a situation of handicap to advance their socioeconomic development and to claim their legal rights, (b) provides people with work and training opportunities, and (c) campaigns for the inclusion of disability rights in new governmental policies and programs. Education is a significant part of her activism work, and Nathalie explained that she and her colleagues at Handicap Solidaire Burkina consistently emphasize gender. As part of her work, Nathalie served as manager for the drop-in center and the Espace Bambino Children's Center, and she led trainings throughout Burkina Faso to teach women and girls in a situation of handicap about their rights and about how to build advocacy networks within their communities. In February, 2015, Nathalie became director of programs. In 2016, she went to work for Fauteuils Roulants and Sud (2016), an organization that develops sports wheelchairs and handbikes for handicapped athletes in the Global South.

In addition to her paid work, Nathalie volunteered and held leadership positions in a number of organizations. Lasting Action for Inclusion Burkina (2017), an organization for which Nathalie developed a crowd funding campaign (Lasting Action for Inclusion Burkina , 2014), promotes equal rights and inclusion for handicapped persons in employment and alleviation from poverty. International Service (2016), another organization for which Nathalie volunteered, empowers vulnerable populations as they gain economic independence and food security through education and opportunities for



work and enterprise. Finally, Nathalie reported volunteering for Light for the World (2017), which is an international and disability development organization that advocates for accessible eye care services and inclusive education.

Nathalie expressed a great deal of pride and purpose in her work. Many of the stories she told during her interviews involved challenges and success stories with her clients and a catalogue of projects and programs that she organized. Nathalie appeared to believe strongly in the power of storytelling in bringing about social change. For example, she shared the following success story:

I recently worked with parents who have an eight-year-old child who has multiple handicaps, severe handicaps. She is unable to walk. She cannot really move her neck. She cannot hear, cannot see, and they've been taking care of her themselves for eight years. When they came to me, they said they were very tired. They had heard that, in my organization, there was a center that would accept or receive a child like this. They themselves wanted, thought about killing the child, but they couldn't do it. The father admitted to me that, because of the child, he didn't want to come home at night. He would come home very very late, 10 o'clock, on purpose, so that he wouldn't have to deal with the child. . . . So I shared my [personal] experience with the parents . . . and just conveyed to them that the child needs their support and love to be able to succeed and to do well. After I shared my experience with the parents, they were just, the father was very astonished and happy to hear that there was something they could do for the child. They wanted all the help and experience [that I could offer]. They became interested in the information that I could give them to help their child. They wanted to know, "What do we need to do, so our child can be like you?" So the child now goes to a special school and is doing well, and I am her friend. And the girl has also made many friends in school.

Nathalie identified as a Burkinabe, Mossi woman with a disability and discussed some of the sociocultural disadvantages of living with this identity.

According to the Burkinabe culture, being a woman is to be poor, is to live in an inferior position compared to the man who is the stronger and dominant sex. You will understand that being a woman in a situation of handicap is to be triply vulnerable: okay as a woman, then as a handicapped person, and then as a woman in a situation of handicap. . . . In my ethnic group, women are submissive and inferior to men. . . . The name of my ethnic group . . . is called ethnic group of Mossi. Mossi is a majority group prevalent in central and northern Burkina Faso,

they are very well organized and are dreaded in terms of leadership and power. In this group, even nowadays women are always inferior to men; women have no right to speak and cannot own land or a flock. . . . This is just one example (sorcery, victim of sexual mutilation, violence of all kinds) that the women of my village are still prejudiced to live. . . . Being a woman in a situation of handicap is to be on the fringes of society, living in isolation. . . . The irony is that most training programs are for English-speaking countries, and Burkina, being a francophone country, is disadvantaged in this area.

Nathalie also addressed the cultural significance of being a woman in her mid-thirties. She said, “Today, my age [also] limits me. I cannot have certain opportunities, such as scholarships, a decent job, have a partner. . . . The weight of culture plays negatively on me.”

Finally, Nathalie spoke about her religious identity and faith.

I come from a Catholic family. It allowed me to learn the human values that positively influence my life. I can easily tolerate the trials of life, and I have a new ardor, a hope as to my future, because I know and am persuaded that God can do anything.

In summary, Nathalie described the development and interactions of her handicapped, woman, educated, and activist identities and the organizing effects of her family relationships, culture/ethnicity, and Catholic faith. Within her family, her uncle helped support her through school, and her mother offered Nathalie encouragement and confidence that she regularly applied to her work as a sociolegal advocate and educator. Nathalie also drew from experiences of rejection from her father and of cultural discrimination as a 30-something Burkinabe, Mossi woman in a situation of handicap, which helped inform her activism work with families, women, and girls. Nathalie’s identity and work as an activist was especially important to her, and she shared how her Catholic faith offered her the values, hope, and ardor that fueled her life and work.

**Nisha.** Nisha, a woman with a psychosocial disability from Sunaula Bazar, Nepal, left me with an impression of an astute mind and strong will. At the time of our first interview, Nisha was 34 years old and worked as a clinical psychologist and General Secretary at KOSHISH. Nisha and I had one in-person interview together, in which we spoke in English, a language she had only recently begun to learn: “One year ago, I could not say one word.” In addition to English, Nisha also speaks Nepali and Hindi. In our interview, Nisha discussed her relationship with her family and her identities as a Hindu, woman with a psychosocial disability, member of her caste, student, psychologist, and activist.

Nisha discussed the intersection of her Hindu and family relational identities as a backdrop that organized her multiple identities, particularly her education identity.

[My religion], it’s Hindu. I’m very secular. It’s very open to anything. . . . My family value, when I was growing up, my father gave me a very right education about the culture. I grew up with very open mind. My father gave that kind of training, and my brothers gave me that kind of training.

Nisha’s family relationships, particularly her relationship with her sister, were significant supports in Nisha’s life. “Before my marriage, my family always supported me. . . . Still [after getting married], I’m strong because of my family. My family is my strength. My sister is always with me; she’s unmarried.”

At university, Nisha experienced a striking interaction of her caste, education, and disability identities. When she was studying psychology at the university, she was the only woman in her caste: “I was alone.” She described “negative competition” among the woman-identified students from different castes. “I also found that the teachers had lots of the same problems.” The stress of this casteist environment began to affect Nisha’s academic performance and wellbeing. “I felt very insecure in that time, and I could not

pass exams because of my caste [identity and experience].” When she was in her second year, Nisha recognized that she was developing symptoms of anxiety and psychosis, and she eventually diagnosed herself with schizophrenia. “I was a psychology student; sometimes life is very ironic.”

Nisha described her experience of schizophrenia, a psychosocial disability, and explained how she persisted in her studies.

I was not stable in that stress and trauma and delusion. . . . And I always thought bad about what the university taught us, suspicious of their acts . . . sometimes, like someone not good is coming. . . . Because I had knowledge about my course curriculum when I was good [prior to experiencing delusions], I was really focused on my education . . . and I was also very involved in analyzing [my experiences and symptoms]. . . . When I went to participate in my examination, I could solve all questions. . . . Yeah, and I completed my masters.

Nisha’s family, student, and psychosocial disability identities intersected as she acclimated to schizophrenia, persisted in school, and welcomed her sister’s emotional support.

My sister guides me when I have delusions. . . . She says, “Go. Go. If you fail, it’s okay. If you pass, it’s okay,” like that kind of motivation that I can. . . . It’s like peer support, you know, very good. She’s not [someone with a psychosocial disability] . . . but a very good human being and can guide me. . . . I did my master’s because of my sister.

Nisha’s activist identity developed gradually after she completed her education. She initially took some time at home to rest and rebuild her confidence.

I stayed home six years. . . . Delusions were there, and it was a barrier to me; but slowly, slowly, I [began to] feel that [the delusions were] not real. And I studied a lot more about my schizophrenia. I know what is schizophrenia, and I compared my life, my thinking, to symptoms of schizophrenia. . . . And one day, I told myself that “It is not my life. I have to do something else in my life.” Then I came out from the house.

Nisha decided that she wanted to apply her psychologist identity and experiences with psychosocial disability to bringing about social change, a decision that sparked her identity as a leader.

At first, I joined an NGO as a volunteer. . . . Yeah and I started to meet psychosocial disability people. I worked with them, and generally, I started to participate in forums. I had to say something about psychosocial disabled people; I felt that I had a responsibility to do something for those poor people who were like me. Then slowly, I developed myself, and now I became a leader in my area.

Nisha's leadership identity further developed and intersected with her identities as a psychologist and a woman with psychosocial disability. She was offered a paid position at KOSHISH, a mental health organization whose mission is to unite people living with mental health concerns and psychosocial disabilities with their families and empower them to advocate for their rights. "In this organization, I can be here as a psychologist, not [just] an activist." In her position, she coordinated a number of programs to advance the rights of women and girls with disabilities, such as a peer support program in partnership with the ABILIS Foundation that provided empowerment training and counseling for women with psychosocial disabilities. Nisha described her work with women with psychosocial disabilities and explained the conditions under which they lived.

They still don't come out. . . . They are locked up in the home. . . . My organization always gives support. . . . We also have a center, a safe home, [and we] rescue from the street women who are experiencing the psychosocial disability . . . [as well as the women who are] locked in the home.

Nisha also became an official trainer on the UN CRPD, and she worked to educate women and girls with psychosocial disabilities about disability rights. She educated health providers and other stakeholders about mental health and human rights, and in her

role as a psychologist, Nisha routinely visited people with psychosocial disabilities in their homes and provided counseling.

Nisha shared some of the challenges she experienced as she developed leadership skills. “Actually, I [also] have social phobia. . . . When I have to say something to the people, then it absolutely exposes myself.” She went on to say that she continued to practice public speaking in the midst and in spite of her social anxiety. Also, as she developed as a leader, she learned how to delegate some of the speaking engagements to other people in her organization.

On a sociocultural level, Nisha discussed the difficulties she experienced as a woman with psychosocial disability in seeking an arranged marriage.

I didn’t marry until 32 because I am a person with a psychosocial disability. It is [because of the] social stigma there, discrimination there. We don’t have any culture of love marriage; we have a marriage council. Men came to me, and when they knew about my limitation, my disability, they wanted to go [away], until I didn’t find anyone. And then I married with [another] psychosocial disability person. It’s okay, because it’s an arranged marriage.

Toward the end of our interview, Nisha spoke about her current experiences and identity as a woman with a psychosocial disability.

[With regard to] the feelings and journey, I’m still sometimes suspicious. . . . So I say [to myself], “No it’s not like that. I’m thinking different things. It’s my problem, psychosocial disability, because of schizophrenia.” And I come out from that kind of problem. . . . If I didn’t become a person with a psychosocial disability, maybe I’m not here doing this stuff. . . . Now I serve the people, women and men . . . sisters and brothers who are in the problem. . . . And it would not have happened if I didn’t [have a psychosocial disability]. . . . And so it makes me always proud. “Yes, I’m a woman, and I’m a person with a psychosocial disability.”

Nisha closed by expressing her strong motivation to continue developing as a student, psychologist, and activist. “My goodness, I want to go further with studies, I

should go. I won't stop my work. I won't stop my studies. I won't stop again in life. I want to go on."

In summary, Nisha described the development of her student, psychosocial disability, psychologist, leader, woman, and married identities, as well as the organizing effects of her family, Hindu-secular religion, caste, psychology education, and culture. Specifically, she learned confidence, open-mindedness, and the value of education from her family and from the way that her family practiced Hinduism. When she experienced the stresses of casteism while studying psychology and began to develop schizophrenia, her sister continued to encourage and support her, a phenomenon that helped Nisha to graduate with her master's degree. Her commitment to studying psychology allowed her to educate herself about and adapt to her experiences of psychosis. Eventually, as Nisha found community and engaged in peer support, she began to dedicate herself to developing her identity as an activist and psychologist. She utilized the knowledge she gained from her studies and from her personal experiences, as well as her awareness of cultural stigma—such as the stigma she encountered while seeking an arranged marriage—to inform her activism work.

**Rojanet.** Rojanet, a woman with a physical disability from Phnom Penh, Cambodia, had a grounded and focused professional energy and a sense of fun that sparkled at the end of the work day. At the time of our one and only interview, Rojanet was 31 years old. She was pursuing her master's degree in development management and working as the senior program officer of the Communication and Awareness Unit at the Cambodian Disabled People's Organization (2016). We conducted our interview in person, but the recording equipment malfunctioned and left us heartbreakingly without a

record of our conversation. Rojanet and I communicated in English, though Rojanet also speaks Khmer. During our interview, Rojanet mentioned her place, family, disability, education, activist, team-leader, and Buddhist identities.

In describing her background, Rojanet shared how place and family organized the development of her activist, disability, and education identities. She was born and raised in the countryside of Phnom Penh, Cambodia, a rural upbringing that later informed her disability rights advocacy. When she was a year old, Rojanet experienced polio (Global Health, 2014). She stated that her family always supported her as a student, activist, disabled person, and human being.

Rojanet spoke about her activism roles and identity. She worked for the Cambodian Disabled People's Organization (2016), an organization with a mission to support, protect, and promote the rights, achievements, and interests of disabled people in order to bring about their equality and full participation in society. Within her role as senior program officer of the Communication and Awareness Unit, Rojanet supervised human resource management, budgeting, and strategic planning and facilitated trainings on media, advocacy, and microcredit businesses. She particularly focused on the concerns of disabled people in rural areas because she knew what it was like to grow up in the countryside. For example, she described organizing a campaign to advocate for cross-disability access to voting centers throughout the country. At the time of our interview, she shared that many of the Cambodian voting centers had new ramps for wheelchair users and tactile marks for blind people.

Rojanet valued the coalition of organizations and projects across disabilities and communities. This value prompted her to undertake a leadership role in arranging the



Association of Southeast Asian Nations (ASEAN) Disability Forum (2016), the purpose of which was to insist that all ASEAN governments sign and ratify the UN CRPD. She also helped coordinate forums for women with disabilities and DPOs, encouraging her audiences to support and attend international advocacy events.

Consistent with her collaborative values, Rojanet strongly identified as a team leader. She described working closely with others to address barriers that women with disabilities face, including lack of access to education, lack of physical access to facilities, and negative social attitudes. She believed that leaders should not tell people what to do, made a point to solicit ideas from all of her team members, and valued the friendly working environments that resulted from validating everyone's perspective. She prized the feedback that she received about being a good team leader.

Rojanet touched briefly on how her Buddhist values helped organize her identities as a woman with a disability, educator, and activist. She told a story about how she learned to overcome attitudinal barriers as a young woman with a disability. She used to feel frustrated when people treated her poorly, but one day, she had a pivotal conversation with a teacher, who shared his belief that the people who treat her poorly are just lacking awareness, not goodness. After that conversation, she found a greater store of patience and compassion for the people who don't treat her well, and she expressed the belief that, with the proper information and experiences, people can come to act with more kindness and respect. Rojanet also described drawing strength from the word of Buddha. For example, she practiced the teaching of putting love and good intentions out into the world and believed that this practice drew love and good intentions back to her.

In summary, Rojanet described the organizing effects of her rural upbringing, supportive family, and Buddhist faith on the development of her identity as a woman activist, educator, and team leader with a disability. In particular, she shared how her childhood experiences of rural Cambodia gave her insights that she utilized in her activism work. Her family helped to give her confidence as a child with a disability and as a student, confidence that she later evinced as she advocated for disability rights. Last but not least, she described how Buddhist philosophy continued to move her toward values of kindness, compassion, education, and collaboration—values that she applied to her professional identity as a team leader.

**Rose-Ann.** Rose-Ann, a woman with a physical disability from Christ Church, Barbados, had a fierce drive and a positive attitude. I will also say that she was as “FAB” as the program of that name, which she helped develop (Fully Accessible Barbados, 2016). At the time of our first interview, Rose-Ann was 45 years old. She worked as the administration project officer at the Barbados Council for the Disabled (2017) and served as the treasurer of the National United Society of the Blind. Rose-Ann and I conducted our first interview in person and our second interview over Skype. Both interviews were in English. Over the course of our two interviews and conversations together, Rose-Ann described her identity as a woman from a family of women, a person with a disability, an activist, a hard worker, a fashionable dresser, a partner, and a global traveler. She also mentioned a number of characteristics that shaped her, such as having an openness to learning and evolving, clarity of focus, faith, and sense of purpose.

Rose-Ann came from a loving family of women that helped organize her identities as a woman, person with a disability, and hard worker. She described how her mother and sister modeled inclusivity and a powerful work ethic.

My sister usually says, “When you were born, you came around with a golden spoon in your mouth.” I was privileged to be a part of a family that was so, so woman, because it was only me and my sister and my mother. My father left before I even knew myself. So I came along at a time when my mother was always doing everything a man and a woman could do. She cleaned the house; she gardened; she did everything. . . . Yeah, she was absolutely the rock of Gibraltar. . . . [She’s] a strong woman, very strong. . . . Even though she can come off a bit strict, she has a really soft heart. . . . So that was a good example for me to live with, to follow. And at the same time, my sister, she is about seventeen years older than me. So when I was born, she was already a teenager. My mother would be out working, and she took up the role of mentoring and pampering and playing with me everywhere. And they never made me feel left out.

Rose-Ann’s experience of growing up with two women who treated her as a valued and equal member of the family helped shape her person-first disability identity and taught her that asserting her personhood was worth making an effort. Her medical disability labels included cerebral palsy (Mayo Clinic, 2017a) and arthritis from lupus, which is a chronic inflammatory disease that can effect one’s tissues and organs (Mayo Clinic, 2014), but Rose-Ann explained that these labels were not overly significant to her identity.

My identity is that I’m a person first and then the disability after, or somewhere far behind. I work very hard to let people see that I’m a person first. It takes a lot of work, and you as a person with a disability have to be ready to put in the work.

Rose-Ann asserted pride in her disability identity, especially in contrast to the moral model of disability and charity ethic described in Chapter II.

I think that because my disability is a physical disability that can be seen right away, immediately it comes up, and . . . this impacts how [people] think, how they interact [with me]. . . . Because a lot of people, when they think about disability, they have this pitying attitude, “Oh dear, oh dear.” It isn’t about “Oh dear” for me, it isn’t. I’m doing what I have to do and what I enjoy doing; I don’t

want you to be pitying me. I am very confident about who I am. . . . This is my life, I don't know how it is to be any other way. . . . If I had to do it all over again, I think that I would choose . . . to be a person with a disability.

Rose-Ann remained aware of her family upbringing and disability identity as she began to raise her critical consciousness and develop an activist identity. When she was first exposed to disability rights activism, she was particularly startled by the injustices that she witnessed.

The fact is that . . . as a young girl, [I was] able to access a lot of the services, able to access education. . . . When I came into the movement . . . we saw and we heard different stories than we were accustomed to—stories about how children with disabilities weren't able to go to school. . . . Some of the parents, they hide them away, and you heard about communities that never even knew that there was a disabled child in a house. . . . So I came into that era with a very quick learning experience. . . . I was twenty-five, and over the years I evolved into what you see right in front of you. I'm still evolving.

As Rose-Ann continued to raise her awareness, she solidified an activist identity. For many years, she sat on the board of the Barbados Council of the Disabled (2017)—a DPO that partners with international agencies and all sectors of the community to champion the rights of disabled people and ensure their full and effective integration into society—and eventually became vice president of the board. She also came to serve as the treasurer of the National United Society of the Blind, an organization that provides services for people who are blind and visually impaired through education, motivation, and mutual respect (Eyecare Caribbean, 2017). Although her paid work did not involve disability at the time, she found herself more and more drawn to disability activism.

You know sometimes when you go to a job, and you're not totally fulfilled? I felt that way. . . . And then suddenly, a job came up at the Barbados Council for the Disabled. A job came up, and I said, "I'm going to give this a try." And to be honest with you . . . I left a high paying job, a job that I had health insurance, a job that I had medical insurance and a pension plan. I just left all of that and went to work at the Council

So Rose-Ann stepped down from her volunteer position of Vice President of the board

and began her work at the Council as a financial officer doing the accounts.

At the time of our interviews, Rose-Ann's activist identity was in full swing as it interacted with her woman, disability, increasingly aware, and hard worker identities. She had become the administration project officer at the Barbados Council for the Disabled (2017), where she facilitated many aspects of the Council's operations, including project reporting, communication with members, and organizational procedures. She helped coordinate Fully Accessible Barbados (2016), a program that assisted and rewarded businesses, such as hotels, restaurants, and other public spaces, for creating cross-disability access. During our first interview, she shared her plans to expand FAB beyond the tourist sector: "We're even going as far as fully accessible education. Is your education system embractive of persons with disability?" Rose-Ann also helped develop the Sexual Reproduction Health program for persons with disabilities, a project completed in partnership with the UN Population Fund to educate women and girls with disabilities on their sexual and reproductive health rights. She represented the Council, facilitated projects, and gave presentations at a variety of community-wide, national, and international forums, discussing topics such as HIV/AIDS within the disability community, child abuse, gender-based violence, disability accessible public spaces, access with service dogs, the physical and emotional benefits of exercise, self-empowerment, and advocacy.

Rose-Ann spoke about the interaction between her hard worker identity and her identity as a woman activist with a disability. She explained,

I'm working at my optimum. . . . Over the past couple of years also I developed arthritis with lupus. . . . I basically just have a lot of joint pain, so obviously, that has also been another factor impacting on my life. . . . For instance, the year before last year, I was in a lot of pain, [but] I did not miss work for a day in the

year. . . . Yeah, because although physically I may not be able to do it, I push the limits.

For the most part, Rose-Ann expressed the belief that the hard work enriched her life:

“My life is so full, really so full. And I even think that I'm getting more accomplished than I ever was before.”

One fun way that Rose-Ann worked hard to express both her womanhood and personhood was through her fashionable dress.

Most of my friends and associates will tell you—not that this should be your trademark—but I think they'll say like this: “You know that Rose-Ann? She's a dresser. She likes to dress.” . . . I love clothes, and I love to dress. I know that, as I'm getting older, it is a must know [about me]. . . . I really like to dress, because a woman that dresses well tells a story, and I'm very meticulous about how I put myself together. . . . Do you believe that first impressions last? That is where I'm coming from. . . . I mean don't get me wrong, there are some days when you feel like hell, but you have to fight it off.

When I asked Rose-Ann what statement she made with her personal style, she replied that she expressed her identity as “a confident, independent woman that is capable of operating all her goals.”

As part of her hard-working identity, Rose-Ann possessed a persistence and clarity of focus that manifested in her identities as an activist and as a partner to her husband. She said,

In most cases, I know what I want. . . . Once I am focused on a goal and once I am making sure I am not pushing anybody aside . . . I will focus on that goal, and I will get to the goal. . . . I remember when I first met my husband [laughs], he was a shy individual. . . . You know there are some people that come into your life, and you can actually tell the kind of person that they are? . . . I have a sixth sense about people, and he was a good person. . . . I was almost like the chaser [in the relationship].

Rose-Ann discussed how disability, clarity of focus, and faith helped organize her courtship with her soon-to-be husband. In addition to being a good person, she described

her partner, a man with a visual disability, as “very analytical,” and shared her imaginings about his thought process as they began a cross-disability relationship.

He doesn't talk a lot, you know, but he's a thinker. . . . And I think that that is one of the reasons that this relationship took a bit longer to get off the ground. Because even although we were friends, I got the impression that he was thinking that, “Hey, here it is that I'm visually impaired, and she has a physical disability. How are we going to mesh the two? When we go to the supermarket shopping, how are we going to get home with the groceries? . . .” So it was all of those things that he was thinking about.

For her part, Rose-Ann felt confident that they would make a good team and laughingly stated that her partner “finally came around to my way of thinking.” She recalled their courtship as “an enjoyable stage of my life” and spoke about her husband with happiness, love, and respect: “I have no regrets.”

In addition to her openness to fostering a cross-disability relationship, Rose-Ann described raising her awareness of how to be in relationship across gender identities.

I grew up in a household with only women, and [my husband] was the first male influence that came into my life. I never had a boyfriend before him. I have a brother, but . . . he lives in Sweden. . . . He wasn't part of our household, so I was never exposed to a male figure. . . . When we got married, it was more of a wake-up call . . . having to learn to deal with differences of view, a man's perspective as opposed to a woman's perspective . . . and that is another area of our relationship that is sort of evolving. . . . It is important [to me] to have a male perspective, [a different] point of view.

Related to increasing her awareness, Rose-Ann spoke about being a world traveler—a professional identity that interacted with other salient identities in her life. She listed some of the opportunities that she has had to travel as an activist with a disability and ended by saying,

I hope that you can take me up and plop me down in any country and I will still be who I am. . . . Barbados is a beautiful place, and I will always promote Barbados, but . . . I am open to any part of the world.

Rose-Ann spoke about the intersection of her world traveler and hard worker identities. She shared that some people in her life tend to glamorize her traveling.

But they don't understand that, when I go traveling the world, I am preaching, and I tend to get so tired. . . . When I go to these conferences, unfortunately, I am only but one person with a disability there. Maybe from the Caribbean or even sometimes at the international forum, I'm the only disabled woman there. So the emphasis is on me to get the word out.

Rose-Ann explained how her faith and sense of purpose, which helped sustain her, were also important pieces of her identity.

How do I do it [all]? I'm not a deeply religious person, right, but I believe that where God has put me, I am supposed to be. . . . And then I might want to do something, and God might be saying, "No it's not the right time," and I have to rest assured that when He is ready, He will put me in that position. . . . Sometimes unfortunately, I grumble. I want to run and hide, but then I realize that, "Hey, you were put here for a reason, you know," and I find that I don't let it keep me down for too long. I don't. I don't know if it is God giving me the strength to go on, but I tend to shake it off.

Rose-Ann expressed the uplifting effects of her faith and sense of purpose while describing an Andrea Bocelli song that she enjoyed.

In your darkest hour, when you think that you cannot go on, there's always something that kind of picks you up and puts you right back on your feet and carries you around the world. Darkness may be before you; darkness may be behind you; darkness may be engulfing you, but at the end of the road, there's always light. If you just stay the course, stay on course, then you will come to the light. . . . You have to, you know, or you will just hide from the world, and it would be like one less light in the world doing positive things. And I think that I have a light that needs to shine. . . . I think that's what we're all here for.

In summary, Rose-Ann described the development and interaction of her woman, disability, awareness, hard worker, and activist identities and the organizing effects of family, faith, and increasing her awareness; she also mentioned aspects of her identity that included being a fashionable dresser, world traveler, and partner to her husband. More specifically, Rose-Ann experienced love and inclusion and witnessed hard work



while growing up with her mother and sister. These family experiences gave rise to her hard worker, woman, and person-first disability identities, which helped organize her increasing awareness, activist, fashionable dresser, and partner identities. Her hard worker identity manifested as effort, persistence, and clarity of focus and contributed to her commitment to raising her critical consciousness. Learning more about the barriers facing people with disabilities launched Rose-Ann into a hard-working activist career with the Barbados Council of the Disabled (2017) and National United Society of the Blind (Eyecare Caribbean, 2017). Her activism work, in turn, included opportunities for her to express her competence through fashionable dress and to become a world traveler. As a partner, she courted her husband with persistence and focus and sought to learn and grow from his perspective as a good person, analytical thinker, and man with a visual disability. Rose-Ann's faith in God and sense of purpose appeared to cradle and organize all the other identities and experiences in her story.

**Sona.** Sona, a Muslim Deaf woman from Abidjan, Côte d'Ivoire, presented as bold, brash, and beautiful; she occasionally and unconcernedly left her interpreters behind in the fervor of telling her story and made a point to show me her colorful clothes and braided hair. At the time of our first and only interview, Sona was 37 years old and served as president of the National Association of Deaf Women of Cote d'Ivoire (Association Nationale des Femmes Sourdes Côte d'Ivoire, 2017). She also held paid work as a messenger. We conducted our interview in person with the help of professional Deaf and ASL interpreters; I communicated in English and Sona in Ivorian Sign Language. Sona also speaks French. During our interview, Sona discussed identities related to family, community, education, Deafness, womanhood, and activism. Sona

shared her family background and explained how her family had a powerful influence on her community-mindedness and personal strength.

I'll just go ahead and tell you a little bit about my background and my growing up and give you an idea of who I am. I grew up on the Ivory Coast. . . . My family is quite large. . . . There are many aunts, and uncles, and cousins, and so many. And kind of the area of the tribe, right in that area, [anyone] could be my kin. . . . Yeah, I'm happy with my family, definitely. Sometimes, you know, there are sad times that we share as well, but we are a community.

Sona also discussed how the generosity of her family has strengthened her sense of wellbeing.

We really never have any serious problems in the family, physical or verbal arguments. . . . We've got means, we have food. . . . I feel for some people who have no means for food. And I know that with my family, though, I might just show up at noon or show up in the evening or whatever, and they're always bringing me something to eat, just to say hello and welcoming.

Family, particularly the influences of Sona's parents, helped organize Sona's education identity. "My parents were very gentle, very nice, nice, nice people to me. And they were very helpful to me and they gave me a lot of opportunities to go to school."

Sona traced the development of her education over time and explained how it set the stage for her future activism work. At school, she witnessed problems with the education system and the effects that neglect and lack of education had on the other Deaf students.

I [initially] went to a mainstream hearing school. At this hearing school, it's like an elementary school, there wasn't really a lot of learning, it was mostly learning through play, and after a period of time, I went to a deaf school. . . . Second grade is when I transferred to the deaf school. And I grew up with those deaf students. And I noticed that there were a lot of problems with their thinking and their behavior and stuff. The teachers worked hard and would work to teach the kids, but they weren't really great. They didn't really teach us a lot. So I was at the school until I was like sixteen. There was the level before high school in our country and I did get a degree from that school. So I thought, "Hmm, I graduated from school." I had a degree, and I thought that it would be a great idea to go to college; but to make that happen would be very difficult because there was no

sign. . . . So I went to a technical school, like a vocational school, to learn how to be a seamstress and to work with textiles. I was there for three years. I saw just a lot of people there, Deaf women in the program, a lot of problems with the community . . . lots of pregnancies [for example].

Sona described an experience that shifted her personal strength into an activism identity and described how activism interacted with her Deaf, woman, and education identities. A Deaf woman from Sona's school became very ill, and Sona tried to advocate for this woman within community and health care contexts.

During the time that this woman was in the hospital for three months, I tried to work with the community to support her, to pay for her medical expenses, to solicit and fundraise to community for her. But no one helped me out.

In addition to growing frustrated with trying to pay her friend's medical expenses, Sona became outraged about the unsatisfactory health care her friend received at the hospital.

Her health declined, and without any help from the community, she ended up lapsing into coma. . . . The doctors and the community just kind of gave her basic care and didn't really work to give her better care from the hospital. So finally, I was able to convince the doctors just to give her something. We went back and forth writing, and finally, he was willing from my pleading to give her some medication to help her. And I had to make some payments to them. From that time on, I just said to myself, we need to improve healthcare.

With proper medicine, Sona's colleague's health improved, which then led Sona to try advocating for support within her colleague's family. Sona accompanied her colleague to her colleague's home in Togo, where she was shocked by the barriers that Deaf women can encounter within their own families.

Unfortunately, when we got home to her country, it turns out that her parents had passed away. So we were looking to find some support for her, and we were able to track down an uncle . . . and explain the situation to him . . . and asked him, "Could you help us out a little bit?" And he just said, "No." And I became furious, and it was this experience that was so pivotal for me—all these rejections and about medicine, which is so important. I was going to do something about it. I just said, "Deaf women need help, too. We can't just be singled out and marginalized." . . . So I went back to Côte d'Ivoire, and I said, "I'm going to dedicate my life to be a leader, and make issues accessible for Deaf women." And I just decided that was going to be my life's work.

The next stage of Sona's activist identity, which involved working with groups and communities, interacted with her identity as a Deaf woman.

And so I called a meeting, a conference if you will, of women . . . in my local community. We pulled all the women together, and I explained to them about this woman's experience and how she was all alone and how if I wasn't there, she would've died. I said, I can't help all of you, you all need to wake up and help take care of your lives and live better lives. We're in this together. [Interpreter's description: Sona is getting up to demonstrate the situation, kind of like doing a role play, a dramatic interpretation of what she's trying to show. She appears to be begging.]

Next Sona's passion drove her to focus on Deaf women's concerns by getting involved in DPOs. She became deputy of women's issues at the Federation of the Associations of the Deaf of Cote d'Ivoire (Association Nationale des Sourds de Côte d'Ivoire, 2016). She also revived and became president of the National Association of Deaf Women of Cote d'Ivoire (Association Nationale des Femmes Sourdes Côte d'Ivoire, 2017), an organization that promotes Deaf women's human rights related to social, economic, cultural, and political participation in Ivorian society. In her role as president, Sona coordinated and supervised all activities of the organization.

Sona's Deaf, woman, education, and family/community identities played important roles in organizing and interacting with her activism identity. She explained,

Currently, the projects that we're working on: anytime a child is born, we set up a donation drive to give necessary supplies to mom and the girls—food, milk, clothes, diapers. We organized a fashion show and invited women to come, and we had six women involved, but the people that showed up—there was a large group of people—so we were able to take advantage of that time to educate and spread some information. . . . We had a presentation about violence, domestic violence. . . . And we also had a soccer tournament, just for women only.

Sona specifically mentioned how her family has supported her activism identity. "So the extended family and our cousins really encouraged me to come here [to WILD], and they're helping me out [financially with my activism work]. Just lots of support that I

have from [my family].”

For the most part, however, Sona utilized her own money to fund her organization.

I ended up having just to sell things and make clothes and jewelry, and with the money that I got, I was able to invest in some transportation. . . . And I was working, going back and forth to Benin and would buy a bunch of materials there and then sell [the clothes and the jewelry] in Côte d’Ivoire. I was going back and forth doing this kind of commute to get some money to make things happen. Because in Côte d’Ivoire we could sell the things there, but we didn’t have the materials.

At the time of our interview, Sona still identified as an emerging leader/organizer and expressed a need for further education to help make her activism work more sustainable.

Just to reemphasize that I need to get some more experience with [running an organization], and I’m really looking forward to furthering my education. It’s so important to me. For example, I’d get training on how to write activities and programs for my agency, how to be a grant writer. I want to know about fundraising and money management. These are so important to me. I want to know how to fundraise and make a situation a little more sustainable, and I’m trying different things and contacting organization and funders, but so far it’s been unsuccessful. I have no idea how to do that.

Sona’s husband had recently moved to Canada to work, and Sona expressed the hope that she might join him to further her education.

And because my husband is there, I have a plan to get some paperwork started for me to go to Canada and live with him up there. . . . When I’m in Canada, I plan to take advantage of the resources and the educational opportunities there, go to college or something. It’s in French, and so I’ll just take advantage of a lot of the opportunities there. And then when I’m done with that, and then come back to Côte d’Ivoire, and just really start working for change with my people.

In closing, Sona discussed her identity as a Deaf woman and explained that her blunt style, which is part of Deaf culture, served her well as an activist.

Well I’m happy and proud to be a [Deaf] woman. Thumbs up! . . . I don’t know, I’m just not a wishy washy kind of waver-y, flounder-y person. I’m blunt. I’m direct. My way is out there. I make things happen, and I step forward, and I’m a

go-getter. Deaf people tend to be blunt all the time, but I just say it as it is. In summary, Sona acknowledged her large, supportive family as helping to organize the development of her family/community, education, and activist identities, to which her identity as an Ivorian Deaf woman was also integral. Specifically, Sona's parents encouraged her to pursue her education. In addition, her extended family offered love, food, encouragement, and financial support, which nourished Sona's sense of community and strength—qualities that later fed her activism work. While attending Deaf schools, she became aware of the many shortcomings of Deaf education and with the lasting harmful effects on the Deaf community—a growing awareness that primed her for her future activism work. She first described taking action when a fellow student from her vocational school became very sick and did not receive the healthcare that she needed, in part due to lack of funds. Sona tried to raise money, advocated with the doctors, and eventually, after much emotional and financial expense, helped her friend regain her health, only to see her friend rejected by family. The frustration and anger that Sona experienced throughout her friend's recovery sparked her dedication to developing an activist identity. She became involved in and began leading organizations (Association Nationale des Sourds de Côte d'Ivoire, 2016; l'Association Nationale des Femmes Sourdes Côte d'Ivoire, 2017) and worked to serve Ivorian Deaf women, with whom she identified with pride. Sona hoped to further her education so that she could enhance her leadership skills and learn how to make her organization more sustainable.

### **Identity Maps**

Through the telling of their life stories, participants drew intricate maps of their salient, intersecting identities. Although many participants had broad social identities in common—Deafness or disability, woman, family relational, education, activist, and

religious/spiritual—the manifestations, salience, and configurations of their identities were as unique as the participants themselves. Participants told very different stories about how their various identities developed, about how certain aspects of their identities organized and interacted with other aspects, and about the experiential moments when their identities intersected with one another in meaningful ways.

Participants' identity narratives wove in and around their social ecologies until the distinctions between identity and context began to blur. Families, schools, DPOs, culture, history, and religion all served as important backdrops for participants' unfolding or intersecting identities. At the same time, those micro-, meso-, macro-, and chrono-systems that were particularly influential appeared also to merge with and become identities in and of themselves. For example, most participants discussed their families both as an influential microsystemic context and as a salient relational identity with meanings and roles that developed alongside, organized, or interacted with their other identities. The wars that Charity and Mbalu lived through represented part of their chronosystemic contexts and also factored strongly into their disability and survivor identities. Similarly, participants' experiences of macrosystemic injustices seemed both to contextualize and constitute aspects of their identities. In other words, participants' most salient identities appeared, from one perspective, to be inextricable from the ecological contexts in which they emerged and developed; from another perspective, participants appeared to carry important ecological contexts with them throughout their lives in the form of salient identities.

## **Normality and Alterity**

In addition to the many salient social identities that participants mapped in their stories, they also discussed times when they identified as normal or as different. Here I include identity results pertaining to normality and alterity with some preliminary interpretation. I include further interpretation of these results and connections to existing theory in the discussion (Chapter VII).

Participants' conceptions of themselves as normal or different manifested and interacted in a few distinct ways. When participants described an aspect of their identity as normal, they appeared to reference the concept of normativity—a combination of descriptive and prescriptive social norms—that contrasted in some way with their identification with alterity. The actual meanings that they conveyed varied, however. They tended to use the concept of normal to refer to themselves as nondisabled people before acquiring a disability, as disabled people who think of disability as normal, or as disabled people who lead normal lives, contrary to social expectations and stigma. When participants discussed their identification with alterity, they tended to refer to intersecting marginalized identities and to their senses of themselves either as social outsiders or as social nonconformers.

When a participant who acquired a disability contrasted her disabled self with a previously normative or nondisabled self, she indicated a shift in her bodily experience or a shift in her identity from being a cultural insider to being a cultural outsider. Atika described herself as a “normal person” prior to injuring her legs and back. As she expanded on her story, she revealed that her experience of her body as well as her experience in society had undergone a significant change. Mayette reflected that she had



been “a very normal child, roaming around from one corner to one other corner” before contracting polio. Even though she was a young child, her body may still have retained a motor memory of moving more freely—an early, formative memory that she classified as normal. She may also have been referring to the evaluative gaze of society. Lizzie detailed the experience of having an accident and of moving “from being perfect, to suddenly having a deformed body,” a phrasing that particularly highlighted the prescriptive power of normativity as a social construct. Lizzie’s story illustrated her experiences of adapting to an unfamiliar body—in form and function—and of adapting to new social representations and reactions to her body.

Other participants thought of themselves as normal within their disability identities and proclaimed their abilities to lead normal lives and to subvert cultural norms and expectations. Bárbara explained, “In my mind, I am just like any other woman. I try to lead a normal life. I think I always try to achieve whatever I want.” Maru said, “That’s one of the things that has helped me a lot: I’ve always done what other people do. . . . I think, [as a person with a disability], you can have a normal enough life, the same as the majority.” Nathalie declared,

For me, being a handicapped woman in my country is being like any other woman in my country. I don’t feel different from others. The only time I think of my handicap is when I encounter an obstacle—having a hard time going up stairs or if I need to get on a bus or something like that. . . . We can be just like other women.

In our first interview, Nandar attributed her confidence and independent living skills to her family’s willingness to subvert cultural norms and raise her as though she were a nondisabled child: “I didn’t have bad experiences because my mother and my family brought me up as a non-disabled person. . . . There were a lot of advantages for me to live as a non-disabled person.” In our second interview, as she described her identity as a

differently abled person, she said, “We don’t like the terminology of ‘normal’ people. We are also normal.”

When participants spoke directly about identifying as different/outsidere, their statements tended to refer to multiple, intersecting identities. Maryana, for example, revealed that she felt like an outsider as a Catholic, Deaf woman living in Jordan. She explained.

I really don’t like Jordan. I don’t like the culture there. . . . I don’t really feel that I’m shown the respect I deserve. . . . I don’t feel like a Jordanian. I don’t think like a Jordanian. I don’t feel like that culture is really part of me. . . . My family is different than that. And so that’s a big issue, you know, that I’m a Catholic and that most of the people around me are Muslim. And that’s one reason why I feel different. And then I have something else. So all of my Deaf female friends, they all wear the headscarves. Just their face, the front of their face shows, and I’m the only one who doesn’t wear a headscarf. Yeah, so that’s another reason I feel different.

Lizzie also identified as feeling out of place in her community as a black, African, disabled mother and wife in a middle-income home.

First of all, where I live . . . it’s a privilege and a curse I guess. I live in a predominantly, I live in the suburbs, let’s just say. And my neighbors and the mommy groups are people with money and wives of people in high positions, and most of them are expatriates that are coming into Kenya to work, so earning big, ridiculous salaries. . . . I mean I have plenty of Kenyan neighbors, but for me, it’s more difficult because disabled people have their place. And disabled people are not, would not be found in neighborhoods that white people live in. . . . If I was the typical 30-year-old African woman living in an affluent suburb, I would be welcomed by white neighbors, but for me, because of my disability, I think they’re curious: “How did you get here? Who are you, or who are you married to? And how did this man [get stuck with you]?” . . . So for me, fine, I may be able to socialize with these women, but at the same time, they still look at me, “Oh you’re African with a disability.” . . . They do; I can always tell.

Sometimes, participants described their identification with alterity as taking more rebellious or subversive forms, even while they might also feel like outsiders. Melba reflected, “It seems like many women who seek change, we’re not . . . conformers.”

Melba, for example, expressed her intersectional identity as a Catholic, spiritual, disabled, Mexicana, activist by engaging in a wide range of spiritual practices and by sending feedback to the Catholic church: “There are many things in the Catholic church that I wish to change, so what I do is contact Catholic priests, and I am always sending criticisms. I also send some solutions through email.” Although Fatima felt like an outsider as a tough, Malawian woman with a disability—“It pains me that I don’t feel the same way as my fellow women [who] feel that they love someone, just because me, I’ve never been in love with a man”—she confidently subverted cultural expectations by refusing to entertain romantic overtures by men. As a Bangladeshi Muslim woman activist with a visual disability, Hen chose to express her identity by wearing the more comfortable “three-piece” garment and by forgoing the more restrictive “crown” or head piece. Mayette expressed her identity as a Pilipino Catholic woman activist with a disability by proudly adopting a disabled son and by openly proclaiming his innate value, lovability, intelligence, and capability to anyone and everyone in her life.

Maryana and Lizzie, who spoke in detail about the outsider aspects of their identities, each found ways to frame their experiences as opportunities to exercise a rebellious or nonconforming identity. Maryana allowed herself to be friendly and social, even when it scandalized her friends.

I’m friendly to people when I’m walking around. . . . Whatever I do, if I’m chatting with a boy, who’s just a friend perhaps, maybe a Deaf friend who is a man, and I’ll say hello, and I’ll chat, my [Deaf Muslim] girlfriends who wear the headscarves, they’ll be like trying to grab my leg, you know, like, making some sort of gesture to me going “no, no, no.” They’re shaking their heads, “no, no, no, no, no, don’t do that.” And they look at me and they think I’m like a prostitute. They say that’s what I’m acting like. And I say, “No, I’m just an everyday person. I’m not a dirty person. . . . This is appropriate.”

Lizzie's story was one of growing her confidence and strengthening her comfort with being different. She shifted from a self-concept of being an outsider to one of an active nonconformer. With regard to her identity as a disabled woman, mother, and entrepreneur, she shared her decision to openly use her crutch in public and to abstain from registering her consultancy as a nonprofit. She also found a willingness to subvert normative expectations when her black, African, middle-income, disabled woman identity intersected with her mother identity.

For me, I think it's always been a confidence thing. . . . I come from a culture of wanting to please everybody [Swahili culture]. So wanting to do something different, something that isn't the norm is scary. . . . So I'm civil [to the white, expat mothers in the community]. I'm not rude. . . . What makes me angry is when they, in turn, treat my daughter different. Yeah, that is what infuriates me. Oh, I'm like a lioness when it comes to [my daughter; laughs]. If I notice the slightest bit of discrimination towards my daughter, oh that does not make me happy, and that's when I speak up [laughs].

In summary, some participants addressed holding identities of being normal people, of living normal lives, of being cultural outsiders, and of being nonconformers, identities that intersected and interacted with one another. Participants who referred to their pre-disability selves as normal implicitly acknowledged their disabled selves as outsiders. Participants who spoke about their disabled selves as normal or who asserted their abilities to lead normal lives implicitly recognized the subversive quality of holding these self-images and of normalizing disability. When participants directly addressed their identities as outsiders, they involved multiple and intersecting social identities in their explanations. Oftentimes, participants' outsider identities had a flip side or silver lining of including a subversive/rebellious/nonconformer identity.

## **Identity as a Preview of Empowerment**

Many of participants' identity stories expressed or implied their empowerment experiences. As their identities developed and strengthened over time, so did their inner fortitude and self-confidence, their engagement with community, and their activism (power-within, power-with, and power-to). Chapters V and VI offer additional perspectives on these identity and empowerment stories. Chapter V addresses important aspects of participants' empowerment journeys, compiling them into a discussion of awareness, barriers, and supports. Chapter VI expands on the actual components or manifestations of participants' empowerment experiences, focusing on participants' approaches to and strategies for advancing their empowerment, as well as on examples of their internal, collaborative, and active power.

All of the topics discussed in the coming chapters—awareness, barriers, supports, personal approaches and strategies, inner strength, and power to act—were also integral to the identity stories conveyed in the current chapter. For example, the contours of many participants' education identity developments appeared to be defined and energized by barriers and supports, as well as by participants' critical awareness about themselves, the education system, or the Deaf/disability community. What they learned through formal and informal education, in turn, affected how participants responded, what actions they took, and how these actions contributed to the formation of their activist identities. Participants' education and activist identities interacted/integrated with other aspects of their identities, influenced their perceptions of and approaches to barriers and supports, and helped them forge new experiences that related to various levels of empowerment.

## **CHAPTER V**

### **RESULTS: THE EMPOWERMENT JOURNEY**

Just as participants described progressions and patchworks of their intersecting identities, they also alluded to and described empowerment in unfolding, multilayered, and intricate ways. While the previous chapter presented the identity results individually for each participant, the empowerment results reported in chapters V and VI are organized according to topics and themes. Because identity and empowerment are complex, interrelated constructs, the reader may need to refer to participants' identity stories (Chapter IV) and to the specific manifestations of empowerment that participants described (Chapter VI) in combination with the current chapter to get a more complete picture of the empowerment journey.

The current chapter offers some highlights of the empowerment journey as it transpired in participants' lives and against the backdrops of their social ecological contexts. Although the themes that appear in this chapter may apply to empowerment journeys in general, I do not intend to make any generalizing claims. By organizing the chapter according to themes, I seek to offer a different lens from one that focused on each individual's story and unique path. By presenting assemblages of participants' quotes, I hope to paint broad strokes of similarities and differences that arose in participants' stories.

Specifically, the current chapter covers how participants (a) conceptualized empowerment as a lifelong journey, (b) set a course for the journey by orienting to education and awareness, (c) emphasized self-awareness as important for navigating the internal landscape of empowerment, (d) shared their awareness of the contextual factors

that influenced their movement through external environments, and (e) reflected on their sense of overall progress. The terrain of the empowerment journey was often difficult and treacherous. Therefore, in comparison with their emphasis on education and learning, dedication to self-awareness, description of interpersonal supports, and reflections on progress, participants' descriptions of environmental barriers make up the most significant portion of this chapter.

### **Empowerment as a Journey**

Many participants explicitly discussed empowerment within themselves, their communities, and their countries as a process or journey. Maryana explained, "Oh yeah, it's a lifelong process. You can't be instantly empowered, you know. It does take time. . . . It's a general process of transformation." Bárbara reflected on her own empowerment by saying, "First of all, I think my empowerment journey is not over. I am in the middle of it, still learning," and Rose-Ann expressed a similar sentiment:

I still think I'm evolving into who I can be. I haven't reached a pinnacle, nor do I ever think that I will ever reach that pinnacle because there's always something new to be learned, you know. . . . Every single day is another experience. . . . That is what life is about. It is about working and evolving and coming into yourself. Charity described empowerment as an ongoing goal of her activism work, saying,

When we're talking about empowering women with disabilities, what I can mention, it's a long way. . . . I think we're in a process, but it's not easy for us. It's beyond the imagination, I think. But we are doing it. . . . It will take time.

### **Orienting to Education and Awareness**

Themes of education and overall awareness pervaded participants' life stories. Many participants traced the development of education-related identities—such as student, learner, or teacher—that were particularly salient to them. As participants discussed their empowerment journeys, they emphasized education and awareness,

discussed times when they became more aware, expressed strong desires to learn, and actively pursued learning opportunities.

Participants oriented to their values of education and awareness at the beginning of and throughout their empowerment journeys. Mbalu explained,

The first thing that gets you empowered is when you are aware of certain things, yes. Because . . . if you are not aware that as a disabled woman you have a right to go to school, you have the right, somebody will treat you anyhow, and you will start off the day and you will just resolve to self-pitying. But when you know that it's a right, there you will start.

Lizzie said,

I feel very strongly about disabled people getting education, and I feel, when you're educated, you're in a better position to make decisions for yourself. It frees your mind, I think, and you're more empowered. . . . When you're educated, you know your rights, and you know how to assert yourself, and you know how to claim your rights.

Charity expressed this idea most succinctly when she said, "Of course when I say empower, I say knowledge."

Oftentimes, participants began their empowerment stories or signaled a new stage of the empowerment process by describing "aha" moments when they awakened to key aspects of their realities. I included many of these moments of awakening in Chapter IV as I shared about who the participants were and how their salient, intersecting identities came to be, but I could just as easily have saved these developmental moments and stories to explore as part of participants' empowerment journeys. Participants remembered moments of awakening that occurred in an instant or that transpired during a particular stage of their lives, and they awakened to a variety of phenomena, which influenced their lives in myriad ways. For example, when Atika had her accident, Bárbara converted to Evangelical Christianity, Charity met other people with psychosocial



disabilities, Maru found a role model, and Nisha realized that she wanted more than a life spent at home, they awakened to a sense of social responsibility and community connection. Rose-Ann's first foray into activism, Maryana's experiences of being tokenized, and Sona's observation of her Deaf friend being rejected by family awakened them to the degree of discrimination and injustice experienced by Deaf and disabled women. Recognizing the degree to which they were dependent on their mothers awakened Bárbara and Mbalu to a drive for increased sovereignty, and practicing leadership for the first time on the sports field awakened Gloria to her potential as a disabled woman leader. When Fatima and Hen went to school, they kindled new hope for their lives; when Lizzie gave birth to her first child, she was more fully able to embrace and inhabit her authentic self; and when Melba saw the delight of a disabled child upon greeting Santa Claus, she discovered her life's purpose as an activist.

Whether their focuses were on formal or informal education, informational or practical knowledge, participants expressed a strong desire to learn, expressions that peppered their stories. "I was only interested in my studies." "Yes, I do love learning very much." "I just wanted to learn more, to have more knowledge." "I need everything, the skills and the knowledge, to be enhanced."

In order to increase their knowledge, skills, and overall awareness, participants pursued formal education, training experiences, and traveling opportunities. They valued their education and travel experiences so much that these experiences factored into many of their salient identities. Lizzie said, "As much as I'm a disabled woman, getting as much education on and exposure to disability rights and relevant issues is important in making me a force to be reckoned with." In describing her return to school after the war,

Mbalu explained, “The thoughts came, and I empowered myself with them: ‘I’m going to school. Whatever I do, take me, let me go.’” Many other participants expressed a similar clarity, perseverance, and drive to learn. “I was really focused on my education.” “I only stayed at home and went to school—school and home, home and back.” “All that I wanted was to pass my exams, do well, and go to the university.” “It’s all related to getting some more education, more training, and I want to get a skill set with that.” At the time of our interviews, all of the participants referenced their hopes either to continue pursuing formal educational degrees—“I want to have my own Ph.D. . . . Why not me?”—or vowed to continue raising their awareness through training, travel, and interpersonal experiences—“Because when we share different perspectives, then we all can improve. We all benefit.”

### **Emphasizing Self-awareness**

Participants showed a strong commitment to self-awareness as part of the empowerment journey. “Building personal empowerment involves reflecting on our personal lives.” For example, Rose-Ann hoped to “generate some ideas within myself—how I can be one of the most effective leaders.” Mayette stated, “Most especially, if we want change, it should start from ourselves,” and Nandar expressed a similar belief: “Whatever you want to do for another person, you need to fulfill that skill for yourself.” Participants’ identity stories offered powerful evidence of their self-awareness. In addition to their descriptions of salient identities, participants’ empowerment journeys appeared to involve self-awareness about their personal strengths, about the environmental advantages they experienced, and about their desires, hopes, and dreams.

Participants demonstrated self-awareness by discussing the areas in which they had personal advantages or strengths. During our interviews, each participant communicated her personal advantages or strengths in a unique style. “A lot of people trust me.” “I have been told that I have charisma and the ability to reach out to people.” “I’ve seen [people] learning, and they’re incorporating a lot of skills which I impart to them.” “I’ve trained many people, and they know me as a good trainer.” “I can motivate other people to become new leaders.” “I can say I am a good team player.” “I’ve always been good at creating relationships.” “I’m well educated, and . . . I’ve got a lot of experience.” “One thing about myself, I’m an organizer.” “I’m a wise manager of money.” “That is my edge, being a leader; I have all this charisma to gather persons with disability.” Even while cultural and individual differences affected the manner in which participants shared their strengths, knowing their strengths appeared to increase their confidence and fortify them on their empowerment journeys.

Similarly, participants showed self-awareness by reflecting on the environmental advantages or privileges in their lives, including God’s blessings, financial stability, areas of access, and the benefits of education and employment. “It’s really so much grace of God that He has given me everything—good house, good parents, everything.” “We were not rich, but we were doing okay.” “In my own home, I have a big accessible washroom. It’s all right with me.” “I did not lack; I was not shielded; I was not excluded.” “My career and my religion are assets.” “We are very fortunate that we are sent from one place to another [to] attend seminars, attend orientations, conferences.” “I was able to . . . go to the university . . . and it just gave me the inspiration and the passion to continue doing my work.” Participants’ awareness of environmental advantages, their gratitude, and their

ability to make statements like “I’m a lucky girl” appeared to offer some protection amid the hardships and demands of the empowerment journey.

Participants’ self-awareness extended to include their desires, hopes, and dreams for themselves and their lives (refer to Appendix I). “There are things that I want to change to be a better person.” “Even though you feel comfortable as an individual, you still need to work on certain aspects of who you are.” For the most part, participants’ aspirations propelled them forward on the empowerment journey.

Many of participants’ desires, hopes, and dreams involved increasing their knowledge and skills. “I want to study more about disability issues.” “I want to learn American Sign Language.” “Hopefully, I can do my Master’s next year.” “I want to learn about other cultures and share my culture.” “I want to learn more about us women with disabilities because we go through many challenges in our lives.” “I also want to learn other languages like French and Spanish.” “I hope to get my PhD doctorate degree in Disability Policy.” Many participants hoped to pursue education in the United States. “I want to come in the United States to study.” “My plan now is that I want to come back to America, if I’m allowed, to have some education.” “If God blesses me, then I will come back to the U.S. to continue at University of Gallaudet, then get my degree.” “I want to come back to the University of Oregon to do some studies.” “I’m thinking that I should come and at least have another degree, a Master’s degree or something that will add to my life.”

Participants also described desires, hopes, and dreams that involved their families and personal lives. With regard to partnership and marriage, participants shared, “I just want some genuine guy who would really understand me.” “I would get married.” “I do

also dream to have a husband.” Some participants mentioned employment and their personal finances. “I hope, if I try, I’ll get an opportunity to work.” “I want to have my own house. I want to have my own car.” “I try and afford my daughter the same opportunities that [other people’s] children have access to.” Other participants shared wistful regrets concerning their families. “Maybe one day, my brother will come to me on his knees, begging for money [and forgiveness].” “If a child had come into my life, what kind of individual would it have turned out to be?”

Many of the desires, hopes, and dreams that participants expressed involved enhancing their leadership skills and holding leadership positions. They spoke to their aspirations as emerging leaders. “I’m not a leader yet, but I am trying to be one.” “Personally, I don’t consider myself a leader, so I want to learn what’s necessary to become a real leader.” “I try to become a good leader, especially for women with disability.” Some participants specifically wished to get involved in law and politics. “At some point I would like to become a congresswoman.” “I would like to become a change maker for the policy of people with disabilities in Asian regions.” “I want, one day, us to get some announcement that [I am] elected to be a parliament lady.”

Participants also expressed desires, hopes, and dreams to locate the funding they needed to continue doing the activism work they loved. “My wish is to have some funding so that I can do a lot of work.” “I’ve got like twenty girls that I want to finance in their schooling, like give scholarships to them, but I’ve not yet started because the fund is not there.” “I want to know about fundraising and money management. These are so important to me.” “I also want to see our organization grow bigger and bigger.”

Participants shared about specific issues that they wanted to address. “I’m

expecting and I'm hoping to get information to [Deaf women] about their rights and domestic violence and all the health issues to just empower them." "It's important for me . . . to have interpreters and teachers who sign. . . . I want to make that change happen." "I'd like to work on bigger projects about inclusion for kids with disabilities." "I want women, and men too, to be included. I want all people with disabilities to work together." "I would like to teach any subject including sign language at the basic school level." "I want to change our country's condition to get more accessibility in schools and universities. Also, I want to advocate at the government level to approve our disability law." "The goal that I have is to encourage or empower other women to also become leaders for [disabled] people and to advocate with other organizations in my country."

Related to her activism work, Rose-Ann expressed the specific desire to leave a legacy:

As you're getting older, your disability will not allow you to do certain things, then added to that, you were diagnosed with a chronic illness which seemingly slows you down a bit. It adds in to the fact that you are not immortal. At the end of the day—although nobody knows when death comes—you have to think to yourself when you die, what legacy have you left? . . . And I want that, to leave a legacy when I die. What do we say about Rose-Ann? And I'm hoping that they say, "She gave her best. She gave her all."

### **Increasing Awareness of Context and Power**

Participants demonstrated strong commitments to raising their awareness of social systems and power dynamics as part of the empowerment journey. "I'm learning so much. I'm becoming so knowledgeable. I'm getting the correct information, and I'm taking it all in. . . . I feel so powerful!" In addition to pursuing formal education and training opportunities, participants increased their environmental awareness through observation and direct experience. "We've seen a lot; we've heard a lot; and we've

experienced a lot.” “I know now very well all that’s happening.” Two main areas of environmental awareness that participants discussed in relation to their empowerment journeys included environmental barriers and interpersonal supports.

**Understanding barriers.** As they expanded their awareness of their multiple, overlapping environments, participants experienced and witnessed significant barriers to the empowerment of Deaf and disabled women and girls. “Us women with disabilities . . . we go through many challenges in our lives.” “I had so many barriers.” “I experienced many difficult things.” “I am challenged everywhere. . . . Look at my world.” “Silently we have cried. Is there any hope for us? . . . The silent cry continues ringing with hardly anyone listening.” The results reported in this section reflect barriers that participants encountered directly on their empowerment journeys, as well as the barriers they beheld in the course of pursuing their activism work.

Specifically, participants described the insufficient knowledge and skills, communication and information barriers, inaccessible environments, inadequate accommodations, economic barriers, limited sovereignty, experiences of violence, and attitudinal barriers that faced Deaf and disabled women. Many of the barriers that participants described fell into multiple categories. For example, violence against Deaf and disabled women can arise from sexist and audist/ableist attitudes and can continue in the presence of insufficient information and awareness, communication and information barriers, limited sovereignty, financial barriers, and inaccessible environments. The organization of barriers in this section, therefore, does not reflect a discreet categorical structure. The decisions I made about how to classify the barriers that participants described reflects my personal thought processes more than the ways that participants

might have categorized barriers themselves. Participants' statements and stories represent the central results.

***Insufficient knowledge and skills.*** Consistent with their emphasis on education and awareness, participants discussed shortages of knowledge and skills as representing fundamental barriers to empowerment. "A lot of people with disability in [my country] are not empowered. They lack a lot of information, any kind of information. They don't know anything." "If the awareness is not there, and if people [in society] are not aware, there's nothing you can do. So that was why we started on that way [by focusing on awareness]."

Participants' identity and empowerment stories often began with explanations of what they didn't yet know. "Firstly, I didn't know about disability." "At the time, I didn't know about social work." "I didn't know really how the funding or channeling of the funding went." "At the time, we didn't know about the special accommodations or special education." "I didn't know how to apply for a scholarship or how to apply for an international school." "I didn't know which school was accessible for me." "I didn't know anything about legislation on disability." "I didn't have much awareness. . . . I didn't know anything about the laws. . . . I didn't know anything about empowerment."

Similarly, participants discussed stages of their empowerment journeys when they lacked practical knowledge or skills. "I didn't have the skills." "All the other students in my class could sign . . . but I didn't understand what they were doing because I hadn't learned sign." "Before, I had no skills. How could I do a job? . . . It was my challenge."

In addition to sharing their personal experiences, participants spoke more broadly about the need for knowledge and skills among Deaf and disabled women. For example,



participants made observations about limited learning opportunities in their communities. “Disabled people in my country, women to be specific, they’re not empowered. Most of them are not educated.” “For Deaf education, [children] only have educational opportunities to the ninth grade and, with that, limited education. Consequently, your opportunities for employment are limited because you have a low education.” In addition to the effects of limited education on employment, participants addressed a lack of vocational and leadership skills among Deaf and disabled women. “There is no skill to work.” “I think, in my country, there’s a lack of disabled people leaders, and I think that there’s a lack of people that have the skills to call attention to disabilities.”

Participants also described a lack of awareness in hearing and nondisabled populations, which created many difficulties for Deaf and disability communities. “The barriers were that people in the environment were not all oriented to how to deal with PWDs.” “Some of the development organizations are very willing to work with people with disability, but they don’t have enough information and they are not familiar with the disability issues and they don’t know how to support people with disability.” “The organizations I target don’t have the slightest clue about disability rights.” Mayette offered a policy example: “Some government officials don’t make an update on their own. They don’t read what is the law for persons with disability and still sign and approve a permit on a building which is not accessible.”

Atika gave a personal example of how the lack of awareness among nondisabled people has had a direct impact on her:

The normal people . . . they are so wrapped up in their own work that it might be the reason that sometimes they’re ignoring . . . the fact that I’m a disabled. . . . By going around me [and thinking], “Ooh, we have to go . . . to the washroom,” they don’t understand that I have to go as well. Just because they can walk easily

doesn't make them so much more eligible to go to the washroom first [laughs].

***Communication and information barriers.*** Participants discussed access barriers to oral and written communiqués—i.e., communication and information barriers—which occurred throughout multiple systems of their social ecologies. “It’s a very difficult life, if you can imagine, not having access to information in society.” These communication and information barriers included a lack of sign language interpreters, an absence of braille or large print materials, and limited access to physical spaces where information was stored or disseminated. Such barriers, in turn, had a very real impact on people’s access to social support networks, education, language development, literacy, safety, health care, and civil rights.

Participants discussed the communication and information barriers that Deaf and disabled women encountered within their family and peer-group relationships. Balkissa shared that she often felt isolated in her hearing family, and she observed similar barriers in the families of the Deaf school children whom she taught.

The parents who have Deaf children . . . don’t sign. There’s no communication at home. So you can imagine a child growing up in a home where they can’t talk to their parents. And so because of this, they’re behind educationally. Their language development, their learning is all behind their hearing peers.

Maryana discussed some of the communication barriers she experienced with her hearing peers: “in general, hearing people always exclude me. . . . They don’t understand Deafness at all. . . . The rest of them are having conversations, and I’m being totally left out.” A participant with a visual disability described the information barriers she encountered around town. “The challenges which I experience are . . . I cannot read ink print unless there is someone that is dictating for me or writing on behalf of me. . . . Especially when I go to the bank, withdrawing the money at the ATM, you have to look

for someone to come and withdraw on behalf of you.”

Participants also outlined communication and information barriers that impeded Deaf and disabled women’s access in school. In their identity stories, many participants described expending incredible effort to access information and education in their lives. Mbalu and Mayette, for example, described the obstacles to accessing physical spaces, such as libraries and classrooms, where educational materials were stored or disseminated. Participants also offered observations about the communication and information barriers that they noticed students facing around them. Balkissa explained, “Deaf people aren’t going to college or university, because the teachers at these places—even at [hearing] secondary schools and schools for the Deaf—don’t sign. So [the students] don’t have access to communication or information.” Maru spoke about the absence of appropriate scholastic instruction in braille: “Right now, what’s happening is that they put the [visually] disabled kids in the mainstream classes, but they’re left there and they don’t learn. They are not taught . . . because the [teachers don’t] know braille.” Nandar also described a rotation system in Myanmar whereby students regularly rotate their positions in the classroom—“Today, I sit in front of the class, tomorrow I need to sit in the back of the class”—and explained how this system places hard of hearing and low vision students at a disadvantage when it is their turn to sit at the back of the classroom.

A lack of access to oral and written information endangered the health and safety of Deaf and disabled women. In her identity story, Sona described feeling horrified at the poor medical treatment received by her Deaf friend, which she largely attributed to communication barriers. Balkissa provided a succinct overview of such concerns:

If a Deaf person goes to a hospital . . . the hospital doesn’t provide interpreters, so there’s no communication. [The doctors] just give the person [treatment for] what

they think is going on. For solutions to the problem, they just make guesses.

Rose-Ann lamented the dearth of information for disabled women and girls about sexual and reproductive health: “There was no program that [addressed] sexuality among the disabled, none at all.” Another participant explained that, due to the dire need for information in braille about HIV-AIDS and for accessible demonstrations of condom use to women with visual disabilities, “Blind . . . and disabled women are dying of HIV and AIDS.” Balkissa drew a connection between information/communication barriers and gender-based violence: “With Deaf girls and women, domestic violence is a huge problem. They need to get help and support, but [because] they never tell anyone what happened . . . they’re easy targets.”

Communication and information barriers also posed a threat to civil rights. Many Deaf and disabled women might not have learned to read, which limited their access to rights-based information. “Oftentimes, if a Deaf person is incarcerated or they don’t know their rights, [it is] because they don’t read and they don’t have access to that information.” Mayette emphasized the importance of visiting Deaf and disabled people in rural areas of the Philippines to disperse information about disability rights: “There are so many people with disability—including women with disability who live in far farm areas—they don’t know what you are talking about here [in the city with regard to disability rights].” Balkissa made a similar observation about Deaf and disabled women in her country:

Mali is a very large country, and there are many women, Deaf women all over the country . . . and not just the Deaf women, but other women with other disabilities . . . who have no access to this information . . . related to disability rights.

Balkissa also gave an example:

In 2008, Mali ratified the UN CRPD . . . and so they passed out this information to people in the country that it was ratified and what it was about, but you have to understand, there were no interpreters, and so the Deaf people were left in the dark about what that meant and how it applied to them and how it would even benefit us.

*Inaccessible spaces.* Access barriers within the physical environment had wide-reaching effects on disabled women as well. “Women with disability have no access anywhere.” “I cannot go alone. I cannot move around in the community as my friends do who are not disabled.” Such access barriers existed in people’s homes, schools, and communities, impeded their use of public transportation, and obstructed their participation in political systems.

Physical access barriers existed in the homes of disabled people and those of their families and friends. “See, the house where you live, the transport, nothing is accessible.” Fatima, whose house was made wheelchair accessible, described the hardship she encountered when she had to live elsewhere.

My house collapsed due to the heavy rains which fell on the night of 13<sup>th</sup> January, 2015. . . . Since the collapse of the house, I have been living with my neighbor, which is difficult for me because of my disability. My house was disability friendly, which was making my life easy, but now staying in a not disability friendly house is making my life difficult and unbearable. Since the collapse of the house, my work has also been affected, because I am not going to work just because of my mobility [barriers], because my wheelchair has been affected as well.

Community spaces also contained a number of physical access barriers, which excluded people from accessing all sorts of systems and services. “In the mall and in all public buildings, they don’t even have ramps.” “Especially for women with disabilities who are in the rural areas, they don’t get an opportunity to get out of their house. They don’t have wheelchair facilities, or the accessibility is not there.”

A number of participants mentioned the difficulties of accessing public transportation—another phenomenon that kept disabled people from accessing their communities. Maru explained the challenges that people with visual disabilities encountered when trying to use the bus:

Public transportation is not accessible at all. . . . For example, we don't have proper bus stops. So, to halt a bus, you just have to watch out for the bus and see the number and stick your arm out. And then sometimes, bus drivers don't even stop if they see that you are a disabled person.

Nathalie discussed the intersection between inaccessible public transportation and barriers to information and education:

In my country, transportation is a problem, and often transportation is not accessible to handicapped persons. So often in transportation, they do not want to deal with the accessibility issues. They don't make space for wheelchairs and for things like that, and as a result, the handicapped persons don't have the same ability to get about or to see places, to go other places. As a result, the handicapped persons do not have the opportunities to learn new things or to experience different regions.

Lack of physical access also created barriers to political participation. Mayette and Rojanet spoke specifically about the need for ramps and tactile markers at voting centers in their countries and across the world to allow access for people with physical and visual disabilities. “During elections, [disabled people] have to vote, but the poll is not accessible.”

***Inadequate accommodations.*** Lack of accommodations was a general type of access barrier that Deaf and disabled people encountered. In addition to needing adaptations to oral and written communications and to physical environments, Deaf and disabled people lacked other types of accommodations, such as additional time, physical assistance, and adaptive technology, to facilitate their participation in society.

Specifically, participants discussed the need for accommodations in school and in the

workplace.

Lack of accommodations posed a barrier to education for Deaf and disabled people from primary school through university. “We never used to have this kind of accessibility you have [in the United States], special education . . . special modules, special attention for these people [with disabilities].” “Our country doesn’t have the technical [adaptive technology] support for all students with disability.” In their identity stories, many participants discussed the lack of accommodations that they personally encountered in pursuing their education. Additionally, Atika, who worked as a study abroad counselor, reflected on the general difficulty of seeking education across the world. “[Disabled students] can easily go for studies [i.e., be accepted into study abroad programs], but the only hurdle they have is accommodation. Universities over there . . . in the UK and Europe and East Asia . . . don’t offer accommodation for disableds.”

Participants specified a few types of accommodations that they deemed especially beneficial. In addition to accommodations that provided access to communication, information, and physical spaces, participants mentioned the need for additional time. “Some physically disabled people are very slow at writing, so we need to get special accommodations to give them more time when they take exams.” They also described needing accommodations for managing books and other school supplies. “My seniors [older students] helped me carry my bag and carry my lunch case. They also helped me to go into the class from my car.”

Participants discussed a lack of accommodations like additional time and adaptive technology in the work place. “With access to employment, the jobs are not accessible sometimes, and they don’t make them accessible.” “If a person has a visual disability and

has to work with a computer, it takes him a long time, and they don't install JAWS [screen-reading software]." Maru gave a personal example of how lack of

accommodations threatened her employment as a teacher:

To maintain your employment, or to have stability in your job, you have to complete an exam in Ecuador- an exam to become a teacher. However, when I went to take the exam , there were no adaptations of the test offered to me [by the Ministry of Education]. Everything was very visual and there was discrimination from figures and graphs. I was given the same amount of time, and it is offered on a computer for two hours. After the two hours, the system closes, and the test is over. . . . I did not have an equal opportunity to other people. . . . That's not okay. The Ministry of Education department talks about inclusion, but they don't adapt any tests.

***Economic barriers.*** Participants described the hardships of scarce resources and financial barriers. "We have women who have disability who are still in poverty, under the line of poverty. . . . They have nothing." Financial barriers arose in multiple systems and constituted substantial access barriers for Deaf and disabled women. Some participants shared about the limited finances or lack of resources in their personal lives. "I don't earn a lot of money, and my parents give me no support." "Our family, we have our own big problems like financial [concerns]. . . . My father's not working. . . . He's just doing some few things in order to find some food for us." "I was totally broke. I had no money." "I didn't have any money. I didn't have any support, so I was kind of on the road, trying to figure out what I was going to do for a job." "I had so many debts. I had to borrow because it's too expensive." "Even my children . . . I don't have money to support them. There was a time when they went to school [and the school officials] chased them back because I didn't have funds." "That [disabled] cousin of mine was not [able to be] breast feeding the baby, and there was no other money to buy some formula for the baby, so the baby died."



Participants highlighted the poverty and lack of resources among Deaf and disabled people in their communities. “The disabled people in my country are really the poorest of the poor.” “Others have no clothes, others don’t have food because they have psychosocial disability.” “[Some people] are taking both medication for their mental [health] and for HIV/AIDS. . . . When you are taking these medications, you have to have a good diet, [but] a good diet is not there.” “A lot of children with disability, a lot of them, they don’t have wheelchairs, or they don’t have white canes, and they don’t have crutches. So this is really too bad.” “There are other blind women and blind men, they don’t get resources.”

Participants also detailed the lack of Deaf and disability-focused resources available in their communities and countries. In addition to describing the dearth of sign language interpreters, braille information and signage, adaptive technology, personal assistants, and physically accessible environments, participants discussed other ways in which their environments were low on resources for Deaf and disabled people. Nathalie mentioned the absence of adaptive sports in her community: “There are many handicapped people who would really excel in some athletics, but we don’t have the proper equipment to support them in that.” Charity depicted the circumstances facing people with psychosocial disabilities in her community:

We only have one hospital, which is Ndera, and even the drugs are not so modern. . . . We need more stores of the drugs for people with psychosocial disability. We need more hospitals. We need more qualified doctors. . . . Also, we need people for counseling, more people who have the qualifications for talk therapy.

Financial barriers often diminished Deaf and disabled women’s access to health care. “They need to have money to be able to afford the doctors. This is for everyone, disabled or not, you need to have funds to be able to access healthcare, to pay for it.”

Mayette shared that both she and her husband needed to leave school in order to cover the health expenses of their multiply disabled son, and Sona told the story of her Deaf friend who almost died because neither her friend nor the community could supply the funds to pay the hospital. Relatedly, Mbalu had surgery for her spinal cord injury without anesthesia because the hospital didn't have the resources to anesthetize her during war time. Balkissa described an intersection between financial barriers, health care, and attitudinal barriers: "Often times if young women who are not married become pregnant, they are scorched from the family, kicked out, so there's no one to help them . . . and they need [financial and social] support."

Financial barriers also affected Deaf and disabled people's access to education. Nathalie explained, "The schools that are available are very expensive, and most of the children who are in need of a specialized school for the handicapped are very poor." Balkissa, Fatima, and Mayette cited financial barriers as the primary reasons they were unable to attend college or finish their degrees. Other participants had similar stories. "One of the reasons I didn't go to the senior high school was that . . . my parents weren't able to pay for it. They couldn't afford it." "I did not find a scholarship." "I could not afford to enroll in a master's program." Mbalu, whose relatives helped her pay for college, explained how she needed to select her courses based on which books she could borrow from her classmates:

I was not able to choose the models that I wanted. I chose a model determined by . . . [whoever] was willing to provide me materials for studying. . . . I'd not be able to choose a model if I didn't know anybody that was willing to help me with materials.

Financial barriers to education had a ripple effect that limited job opportunities for Deaf and disabled people. "If they don't get education opportunities, they also don't get

job opportunities.” “Your opportunities for employment are consequently limited because you have a low education.” “There are a lot of problems like no education and no jobs.”

The lack of job opportunities, in turn, weakened Deaf and disabled people’s financial situations and diminished their access to resources. “I’ve been trying to work since 2005 . . . to find a wage . . . but nothing.” “I had no options.” “We have a lot of barriers—labor barriers in the workplace.” “The socioeconomic situation is hard in terms of getting work for the disabled.”

The top issue that I see for Deaf people in [my country] . . . is that they can work, but there are no opportunities for most people with disabilities. . . . Some people with other disabilities have work [with] a minimal income, but for the Deaf, there’s no work.

“[Employers] have a very limited quota in reservation [for Deaf and disabled people].”

“There’s no disability quota.” “Without a job, how can you live? You are very dependent.”

Participants reported performing some or all of their activism work without pay, which presented additional barriers to their economic empowerment. “I realized I couldn’t get a job . . . so I would volunteer. The first organization I worked at, I offered to work for free, so they took me in, and then the second one, the same thing.” “They said, ‘Okay, before [we give] you a job, you have to do volunteering.’” “At first, I joined an NGO as a volunteer.” “I do voluntarily so much work.” “For my founder organization, I’m the president, but I do [the work] as a volunteer. I don’t get any salary or facility.” “I don’t have money. . . . I’m not paid. . . . I’m doing [this activism work] for volunteering.” “I’m working hard, but it’s not so easy for me to help my children, my family.”

“Oftentimes, I’m doing activities and things, and I’m just barely scraping by. . . . I can’t keep making the organization run with my own personal funds.” “As of now, everything

which I'm doing is unpaid, because we have never found the funding which we can use to run our organization."

Locating funding to support their organizations and their activism work was another challenge that many participants faced—a challenge that had both personal and community-wide impacts. Charity outlined the financial difficulties of founding the National Organization of Users and Survivors of Psychiatry in Rwanda. "Starting that organization, it was so difficult for us. We had no office. We had no other equipment . . . like paper . . . pens, pencils, a computer]." At the time of our second interview, she went on to describe the present-day challenges:

We have a lot of challenges because we don't have funds. . . . We are renting [our office], and even renting, it's not so easy for me to pay every month. . . . Another thing, we're having a challenge of not having transport to take our people to the hospitals . . . if someone gets into crisis.

Fatima described a similar lack of funding for the Forum for the Development of Youth with Disability. "It's really difficult to run a program without any assistance or without any financial resources. . . . How can I impact . . . I don't have resources. I don't have transport. I don't have anything." Several participants described trying to use their limited personal finances to fund their organizations. "At times, I used to give . . . my own personal money, but even when I do . . . I know it's not enough. How much would that money do? It's not enough." Even working in The Department of Social Welfare and Development of the Philippine government, Mayette cited a lack of available funding. "In this office, there's no funding support. . . . Funds are still minimal for implementing our program and services."

***Restrictions to sovereignty.*** Participants described barriers to the sovereignty or personal authority of Deaf and disabled women. Mostly, they described sociocultural

restrictions that kept Deaf and disabled women indoors. They also touched upon some law and policy restrictions that posed significant barriers to the equal participation of Deaf and disabled women in society.

Participants offered background information about the sociocultural restrictions placed on Deaf and disabled women and girls, particularly as they pertained to leaving the house, going to school, and getting married. One participant explained,

When you're born with a disability, especially [in my country], because of culture, some people believe it's a curse, and so you're kept hidden. You're not allowed to go to school. . . . [Then] when you're an adult, you haven't had a lot of exposure with mainstream society.

Other participants made similar observations. "Some of the parents [of disabled children], they hide them away. You'd see the prop families, but you'd never know that a family has children with disability because they kept them hidden away." "Parents of children with disability, they don't accept that they have children with disability. They don't take their children to school." "Children with disabilities weren't able to go to school. They weren't." "[Women with psychosocial disabilities], they are locked up in the home." "[Women with disabilities], they cannot go out [because of] family bonding, social bonding." "In [my] culture, women with disability, they cannot go to marry." "In our country, most of the disabled people are very quiet and keep in their houses. They have no voice to talk about their needs, their rights, their feelings."

Several participants discussed their personal experiences with families or cultures that expressed concerns, ranging from mild hesitation to complete opposition, about allowing them to leave the house or participate fully in society. For example, Nandar spoke about her childhood, saying, "I never went out alone. . . . [My family] took care of me a lot, and they worried for me a lot." Balkissa said, "Where I grew up, my parents

didn't allow me to do much. I couldn't go outside or do much outside of the home. . . . My parents were so limiting and wouldn't let me go anywhere." Fatima said of her childhood before going to school, "I was in . . . the world of just being home without using a wheelchair, without going out anywhere." Hen said, "My family was positive [for me] to study but not to go outside. This is my challenge. And they didn't give [me] permission to work everywhere openly." Maryana described restrictions in aspects of her work life, saying, "[My colleagues], they never let me be in the forefront of things. I always have to be in the background."

Many other systems had policies that deterred or prohibited the participation of Deaf and disabled women. For example, school officials forbade Maru, Balkissa, and temporarily Mbalu from attending mainstream schools. In her first interview, Charity described a discriminatory law in Rwanda's sociopolitical system:

In my country, people with psychosocial disability cannot vote, and are not supposed to be voted [into political office]. . . . Nobody should stop someone from voting, because the right allows him or her to vote, as it is said in the UN convention.

Another participant described how disabled people went unheeded by police: "Whenever they went to the police station, [the police] would not take statements from them. They would tell them, 'Go out. Sort this out yourself.' So that was a very big problem." Still another participant described lacking freedom of expression in her country: "If I did express how I truly felt, I could be arrested and put in jail, and there's no way I want that to happen. They could even hang me for expressing these things."

***Violence.*** Participants described emotional, physical, and sexual violence that they became aware of, witnessed, or experienced in their lives. They expressed deep concern about the pernicious effects of violence against Deaf and disabled women and

girls and described its sweeping consequences. They discussed how the issue of violence connects inextricably with barriers to safety, women's health and wellbeing, access and inclusion, social participation, and individual sovereignty.

Participants shared background information about the physical and sexual violence that Deaf and disabled women and girls experienced. "A lot of girls who have disability, they are abused by men. . . . Each and every day we receive those cases, so that's the [greatest] challenge in my organization." "A lot of rape cases are increasing [among] those girls who have a disability [as compared to] those girls who are normal. Why?" "Women are being raped. Those who produce children are being taken. Others are hidden . . . because they have psychosocial disability." "Even the children are suffering. They are there on the street. They are being tortured. They are being chained. . . . It's beyond the imagination." "In my country, women with disabilities are victims of sexual violence, and many die during childbirth." "[Deaf and disabled women], they're also victims of sexual abuse and HIV and AIDS." "Disabled women are dying of HIV and AIDS. . . . Men are using us blind [people] and people with disabilities in terms of sexual activities, then they like leaving us, just like that. They just take advantage." "A lot of murders . . . [Even women] who have no disability, they're always suffering. . . . The dowry and pressure and physical torture." "Recently, we've had a strain of domestic killings. A number of women have lost their lives at the hand of their partners." "It's so challenging because, men in [our country], they do abuse us so much, so a person cannot have a free life."

Participants also discussed the exploitation of Deaf and disabled women. "It's quite often that women are forced to go to work and by men, to sell things on the street.

And the money that they earn, the men take away from them.” Sona spoke specifically about the exploitation of Deaf women through sex trafficking:

There are people from . . . different countries, they come to Côte d’Ivoire and entice [Deaf women], steal them, take them away back to their countries with the promise of funds. But they take advantage of their labor, and [these women] are taken into the sex trade. And once they become pregnant in these situations, then they’re just dropped off back in Côte d’Ivoire, and they’re pregnant on the street. They are just left. And [the sex traffickers], they’ll go find another person to entice with the promise of funds to go out of country. A lot of the [Deaf] girls are in that situation. It’s a high level of shame.

To better illustrate the dire situation of Deaf and disabled women and girls, participants told individual stories of the people they served in their organizations who experienced violence. In sharing about her activist identity, Nathalie told a story about a multiply disabled girl whose parents contemplated killing her. Other participants told similar stories about the violence they addressed in their work.

Mbalu, for example, shared about a girl she met on an outreach program and the physical abuse the girl had experienced at the hands of her family:

There was also a case of a six-year-old girl. The mother was a single parent. And [with] all the stress she had got from the girl’s father and the girl becoming disabled, she was so stressed about that. She kept on beating the girl up all the time. Then one day, I went out for an outreach program—because I used to go with a team. And this girl, I said, “Come.” I was trying to play with her, but she was just crying. She was so nervous. Then I turned to the teacher . . . [and] the teacher said . . . “Everybody in the community knows that this mother is abusing this girl by beating her up for little things.”

Charity gave an example of police violence toward people with psychosocial disabilities:

There was a person who had mental disability. He was a leader at first, and then he came [to develop] psychosocial disability, because he’s a survivor from the genocide. . . . One day, he went into crisis and he pulled up the [electricity meter in his neighbor’s yard] . . . and the neighbor was a policeman. What the policeman did was to take him to the police station [where he was] imprisoned,



and they tied him. The whole arms were tied like chaining, and even the leg, they chained from the leg to the hands. Then after chaining, [they left him for] a week.

Charity explained that, by the time the man was discovered, his injuries were so profound that he needed to go to the hospital. “They said ‘We have to move this man because this man is going to die.’” Due to infection caused by the restraints, the doctors at the hospital decided that they needed to amputate both of the man’s hands. In reflecting on the incident, Charity exclaimed, “You know, the police are lawmakers, they’re not supposed to do that!”

Fatima described the abduction and rape of V, one of the students from the Learning Center where she worked.

There’s this other girl, [V], she’s mentally disabled. She has been the victim of rape seven times. Imagine that! . . . She’s a girl, and she [became pregnant]. . . . She’s one of my students at learning center. So she was coming from the learning center [when she was abducted]. . . .

V’s parents called Fatima when they noticed V was missing, and Fatima joined them in a search for V that lasted into the following day. When they finally found V, they rallied community support to help remove her from the kidnapper’s house, and they initiated legal proceedings against the kidnapper.

As she continued the story, Fatima touched upon the intersections among violence, financial barriers, health barriers, and restrictions to individual sovereignty. Fatima described waiting and waiting outside the courthouse to testify in the trial, only to learn that the kidnapper’s family had posted bail and paid money to V’s parents to drop all the charges. When Fatima confronted V’s parents, “They said, ‘Yes, we received the money because we had nothing to our home. We had no money. We had no mill flour, things like that. That’s why we received [accepted] that money.’” Fatima described the

mental health repercussions of V's trauma. "After being abused by men, she can't narrate everything in front of people. She can't speak everything. . . . She loses things."

Moreover, in an attempt to protect V from further abuse, V's parents decided to restrict her sovereignty. "[V], from now on, should not come out of the house, just to save her."

Fatima emphasized their intentions: "We are not abusing her, but we are saving her."

Some participants chose to share their personal experiences with violence. In their identity stories, Charity, Hen, and Mbalu attributed the origin of their disabilities to the violent injuries that they received. Other participants disclosed their experiences with violence as well. "So we did have sex. We did, and I couldn't tell my parents about that. I had to keep it to myself. After that . . . he told me that I was dirty. . . . I feel so used. I've cried and cried." "It is so stressful to wake up every day to a new email, threat, or message that demands that I leave or threatens to hurt me."

There are many men in the country, in my city, they really don't like me, and they've threatened me with physical harm because I'm telling the women to keep your legs closed and don't let men take advantage of you. So many men have threatened me with physical harm because of my work with the women.

Melba described experiencing frightening harassment by her boss from a previous job.

So the biggest barrier I had to face and the person who prevented many things from happening was the boss I had in my past job. . . . He wouldn't let me leave the building or give speeches. . . . He forbade my work mates to help me with my work. . . . One day, he came to me and said that I could not work with my computer anymore and would have to work without it, and he gave it to somebody else. . . . He even once threatened me on the phone on the weekend. . . . So he called me on my cell phone to threaten me and say that if I continued to speak out and tell what he was doing, I was going to regret it. So when I received that call, [I was so affected that] I could not move from my chair for three hours.

Mbalu touched upon the intersections among violence, access barriers, and financial barriers by sharing some stories about professionals in the community who

withheld their support until she paid them large sums of money. She described her experiences with taxi drivers who trapped her in their vehicles or refused to return her wheelchair from the trunk until she paid them more money than they had initially agreed upon. She also described going to a government office after the war to claim a disability check. The first barrier she encountered was the steps: “How could you say you're going to compensate disabled people, and they have to climb down something like twenty-five steps, if not thirty?” Once she received the check, which was smaller than she had anticipated—“Three hundred thousand leones. At that time, it balanced to a hundred dollars [laughs].—she found herself stranded. “The guy that took me down those steps, as soon as they gave me the money . . . he said, ‘Let me have mine, or else I’ll not carry you up the stairs’ [Laughs wryly].” She resignedly paid him to take her back up to her wheelchair.

***Attitudinal barriers.*** Negative preconceptions and attitudes were some of the barriers that participants found most pervasive. “There are social barriers, the attitudes of people who still don’t understand or who are not sensitive to people with disabilities.” “Prejudices, many prejudices.” “In some of the areas or some of the society, there is a lot of discrimination or negative attitudes on the woman and also on the disability.” “There’s this stigmatization, a lot of stigmatization about being a disabled person in my country.” “Deaf women need help, too. We can’t just be singled out and marginalized.” At least in part, harmful attitudes appeared to interact with all of the other types of barriers reviewed in this study—insufficient knowledge and skills, communication and information barriers, inaccessible environments, inadequate accommodations, economic barriers, restrictions to sovereignty, lack of social participation, violence, and exploitation.

Participants observed and encountered such attitudes in the form of hurtful words, interpersonal rejection, and exclusionary behaviors that reverberated throughout their social ecologies. Such stigma arose in families, schools, workplaces, governmental and nongovernmental organizations, Deaf and disability communities, and the wider sociocultural environment.

Some families held attitudes that left Deaf and disabled women and girls feeling restricted, rejected, excluded, and unloved. “Every parent has worry for their children, but worry makes barriers to get in touch with the environment, to get in touch with the society.” “The family was thinking that way: ‘You’re going to be a burden. You’re a burden.’” Balkissa cited her parents’ shame of her Deafness as their reason for keeping her out of school and in the house for three years. Bárbara’s mother, who acted as Bárbara’s personal assistant during childhood, occasionally told Bárbara that she was an encumbrance. Hen’s family feared for Hen’s safety and social propriety and asked her to quit her job and turn away potential suiters, and Nathalie’s father rejected her and her mother after Nathalie acquired a disability. An anonymous participant shared her personal experience of rejection by a member of her family:

When I was [hearing/nondisabled], my brother, he just loved me. He spoiled me. I was just like his baby . . . but then when I became [Deaf/disabled], my brother disowned me. He wouldn’t provide any support for me. All that love and all those cherished moments I had were gone. They were taken away. I was almost like a stranger. It was like he didn’t know me. I’d be sick and shaking, and he’d just walk around me—wouldn’t help me at all.

Fatima shared the story of a blind man she knew:

He was born normal, but since he became blind, his family, they started not liking him. They no longer love him, so he’s facing a lot of challenges. . . . He says now just because he’s blind, he’s no longer part of his family.

Participants discussed specifically how families' low expectations and negative attitudes, as well as their experiences with financial barriers, kept Deaf and disabled children out of school. Fatima observed,

Parents who have children with disability . . . they don't take their children to school. . . . A lot of parents say, "I'm not seeing any [potential] benefit from this child." . . . So they tell those children with a disability that they can't be breadwinners [for the family] in the future.

Nandar reflected, "The parents in the rural areas, they are not well educated, and their attitude is to only take care of these children [with disabilities] to be well [healthy, but] not to be educated." Mbalu shared,

The parents will say, "Well, we prefer to pay for the abled students rather than this one. At least those who are able, they have more prospects. We are having so many children. We are poor, so it's better for us to pay for those children that we think have more prospects than to pay for a girl, a disabled girl."

Sociocultural stigma also interfered with the education of Deaf and disabled women and children. "The children who are either blind or deaf do not have the same opportunities to go to school like other children who are not blind or deaf. . . . [School officials] don't want to enroll them into the schools." "Some schoolteachers are able to assist students with disabilities, but not all. Some have a bad attitude." "They don't approve of women gaining knowledge. They think we're not capable of learning and that we should just be passive and accept what's going on and do everything for the man . . . while we don't do anything for ourselves."

Participants' identity stories were rife with personal examples of how sociocultural attitudes presented barriers to their education. Maru described leaving a mainstream elementary school because her teachers believed that, as a student with a visual disability, she could not be taught. Balkissa shared that she had to leave a hearing

high school because the parents of the hearing students feared that their children would catch deafness from her. Although she was ultimately able to stay at her high school, Mbalu described experiencing significant emotional distress after the administration tried to expel her for requesting a ramp. Another participant, who preferred to remain anonymous, recalled a particularly stinging rejection: “He looked at me and said, ‘Oh, you’re [Deaf/disabled] and you have no future, so why waste money on paying for you to go to senior high school?’ So I was denied that opportunity.”

Additionally, participants recounted the attitudes of prospective employers around the issue of hiring Deaf and disabled women. “Discrimination is very big, [so] there are a lot of problems like no education and no jobs.” Mbalu reflected,

When people apply for a job—you’re disabled, you applied, you have all of the qualifications—they will say, “Ahhh, we want to take this person. I think he or she has what we’re looking for.” [But] as soon as you appear, they see that you have some physical challenges, they say, “Oh, you know what, we’ll get on to you later.” That’s the end of it. . . . So at the end of the day, it’s a big discouragement.

Balkissa explained,

People don’t employ people who are Deaf. There are some women who work in positions in the fashion industry; there are a couple of people, but most Deaf people in the country have no work. For example, there are many, many women who could do work at restaurants, in the hotel industry—to cook and to do bussing and to take orders. But when they apply and they go for the interview, as soon as employers find out that they’re Deaf—they don’t even make it through the interview, because the problem is they’re excused straight away. So that’s the first big issue or problem—there’s no work.

Gloria observed,

If a woman applies for a job, the interviews are conducted. At some companies, they choose a woman who is abled or a man who is abled, rather than a woman who is disabled . . . because they feel it will be difficult for her to move around quickly . . . or whether she’ll be able to sit for a long time before the computer and work, or, if she will be using her braille or JAWS, whether she will be able to do this work. All these questions will go on within their mind, and they will underestimate the capacity of a woman with disability.

Participants shared their personal experiences of how negative attitudes and expectations limited their employment opportunities. Gloria and Mayette both spoke about passing exams in the banking sector but being denied interviews when employers learned they had disabilities. Charity's employers asked her to leave her job once they learned about her psychosocial disability "I was working as a bank manager, but when someone goes into that sickness of psychosocial disability, most of the people say, 'She can't manage.'"

Even when Deaf and disabled women secured employment, discriminatory attitudes continued in the workplace. Melba described being passed over for a promotion, for which her boss, who had previously held the post, strongly recommended her. "Instead they gave the job to another [man-identified] boss who was not disabled and had never worked with disabled people." Gloria gave an example of the professional exclusion of disabled women that she noticed around her:

In my work . . . I have seen, especially in rural areas, women are suppressed more. And if they have this disability, they are even discriminated all the more. So, when there is some local elections going on, in panchayat level, village level, if a woman candidate stands for the election—if she wants to become a panchayat leader or a councilor or a board member—there will be a lot of men who will oppose a woman becoming a leader. After all the struggle, if she wins with the support of her family members . . . she would not be able to take any decisions. It would be her husband sitting at home and deciding things. . . . He will have all the power. He will be roaming around the village as though he's the leader, and the woman will be sitting in a corner.

As they sought coalition with governmental and nongovernmental organizations, participants described the othering that they encountered as Deaf and disabled women activists. Nathalie observed, "When I go to organizations that deal with children [without a disability-specific focus], the big problem that I encounter is that they're not open to

dealing with children who have handicaps and that they treat children who have handicaps as though they're not like other children." Lizzie expressed disappointment:

When you think you have made connections with people, with organizations who are really not interested in working with you, that's sad. . . . I wonder if there will come a time when organizations, decision makers, policy makers will take disabled people seriously.

Melba reflected, "A few times when I've talked to senators or congressmen that are men, they think or they have led me to believe that talking to a woman with disabilities is basically like doing her a favor." Maryana shared her experience of feeling rejected by a hearing activist.

[This person] seemed to prefer the people that she could directly communicate with, and I feel that since she couldn't communicate with me, she looked down on me. I think she looked down on me as not educated enough, and she was using my second language of Arabic to base that decision on and saying that my written Arabic is not as good as it should be. My first language is Jordanian sign language!

Participants often deplored the charity ethic of disability, an ethic entrenched in the moral model, which casts disabled people as pitiable, assumes they need help, and allows them to be controlled by charities and social service institutions that never consult them directly. "We don't want others to feel pity for us. Sympathy is not required." "Disability, first, isn't a curse. It isn't something that happened to you because you did something wrong. It's not your fault." "There are no easy options for [Deaf and disabled people]. People treat you with sympathy but not as a normal human." "They're coming from a perspective where the disabled ought to wait for pity or charity contributions or something like that. . . . They tend to look at [disability] as some kind of charity. It's not. It's actually [about] rights. We have rights."



Participants also identified the intersections of audist/ableist, sexist, and racist/colonialist attitudes that they encountered while working with activist organizations from Europe and the United States. “We are disabled women from developing countries, and sometimes, it feels like a circus act, being paraded around. . . . I guess we are supposed to be as native as possible . . . come in skins and that sort of thing.”

“Globalization has taken place, and America is not that far-off place that people don't have access to. . . . We go to school, we learn, we know your history, maybe even more than some Americans. . . . We don't live in trees.” “They used to tell us that, generally, Latinas from Peru, Ecuador, Colombia, Mexico, they always used to tell us, ‘You have to try not to talk so much.’”

I think the stereotype of who a disabled woman is in Africa, even the organizations wanting to work with you look at you like you don't have an opinion. I don't want to do the typical work, “Oh let's get the beads and do bead work.” That's all well and good, but I think for me that defeats the purpose. The whole point is to integrate people with disabilities into society.

Participants expressed disappointment and dismay that competitive attitudes and jealousy arose within the Deaf and disability communities themselves. Mbalu shared about the sexism she encountered among disability activists.

I'm also having a problem now as an empowered woman. The men, the disabled men are looking at you as if you want to challenge them, you know. . . . They don't think you are partners in development. . . . So it's hard for them to come across an educated young woman like me who is on a [wheel] chair.

Melba observed,

There is one barrier that I identified only a short while ago that has to do with prejudice but with the prejudices that the very people with disabilities have. . . . In my team, everybody has a disability. Other people with disabilities see us, and they see that I now have a position as a director, and they think that I got to that position because I am either a friend or a daughter of someone who has a lot of power. . . . So they put up a barrier and start thinking that I am there for reasons different than my own capacity.

Bárbara noted,

Quite a few people like to brag and be the center of attention, particularly older leaders who don't want to lose their positions. They also don't appreciate upcoming leaders, particularly women. . . . There is also a lot of envy and jealousy among colleagues who head similar disability programs. Since most people interested in these issues tend to approach me for interviews regarding my program, the result is that many of my colleagues feel envious and tend to criticize my activities.

Sona reflected,

Many of the other [Deaf] women there are jealous of me. I provide a lot of workshops, trainings, and festivals with activities and food, etc., in my association, and they look at me like, "How can she afford all this? What is she up to? She wants something back." And there's a lot of backstabbing and criticism on my own generosity and my work. I don't get it.

Gloria relayed her analysis of how attitudinal barriers and limited opportunities for disabled people created extra tension within disability communities. "[Employers] have a very limited quota in reserve [for disabled people]. How can so many [disabled] people get the job? . . . So it is very difficult for them [because] they also have to compete among themselves."

On a sociocultural level, participants shared the pain of encountering negative attitudes. "I do have people laughing at me." "It really hurts for someone to say, 'Ha, this person has a psychosocial disability. She can do nothing. After all, he/she's hopeless.'" "The [hearing] people there, they don't look at me and recognize that I'm able, that I'm an able person, just like anyone else. They look at me and see me as lesser than them." "These people, they don't want me here." "People think that when you're disabled, you're finished. . . . Even friends abandon you. . . . And in society . . . when you're in a wheelchair, driving it out there in the streets, people will look at you, you will just want to disappear."

Some participants discussed the role of language and labels in perpetuating ableism in society. Charity's husband told me that the traditional term for a disabled person in Kinyarwanda means "broken pot." Nandar shared something similar about trying to change terminology in her language and culture. "In Burmese, [the term for disability] means not strong, and not abled. . . . This meaning is so negatively impacting to our decision-making [process]. . . . We don't want that."

Participants discussed how discriminatory attitudes presented barriers to the sociocultural institution of marriage and to the role of becoming a mother. "Men do not want to be with women who are disabled, so often, as a result, the women end up staying single. . . . If they do have children, they don't know the father, so the father is not involved." "When a woman with a disability is pregnant, a lot of nurses or doctors may ask, 'Who is that man who did this to you? . . . And why did you do this?'" "At times when you are pregnant and you go to the hospital, they'll just hit you [with], 'How did she become pregnant? Who is the man that will admit it?' As if it's not normal, you know [laughs]." "The society that we live in here is so judgmental. Some foolish person wants to say that 'You have a disability. . . . How are you going to take care of this child?'" As part of their identity stories, Nandar, Gloria, Hen, and Nisha reflected on the negative attitudes in their societies around Deaf and disabled women getting married and having children. Mbalu also shared her personal experience:

I was having a boyfriend, and he was so kind. He wanted to do everything for me. He went to the university; I went there along with him. When he finished [graduated], he said, "I'm not going to marry you" [sighs]. So that was how it ended.

**Appreciating supports.** In the process of discussing how they navigated or surmounted the barriers on their empowerment journeys, participants highlighted the benefits they derived from experiencing interpersonal supports. “I get a lot of support from my social network.” Just as they demonstrated self-awareness by recounting their environmental advantages or privileges, participants acknowledged and expressed gratitude for the people who supported them. Specifically, participants described benefiting from supports in the forms of encouragement; direct assistance; and love, acceptance, and professional respect.

**Encouragement.** Participants recognized the supporters in their lives who encouraged them to carry on and to realize their potential. “Oh, thank you! Thank you for your encouragement.” They mentioned family, friends, and colleagues who had a positive impact on their lives.

The encouraging words that participants received from others stuck with them and played an important role in their motivation. “A lot of encouraging words [can] help me as kind of a refuel to feel strong again. And that support [can be] invaluable.” Many participants recalled encouraging words in their identity stories. For example, Hen appreciated the encouragement of her mother and elder sister, who said, “You can go. We are with you.” Mbalu recalled the name and the words of the staff member at Handicap International who urged her to pursue her education: “He also was encouraging me, ‘You should go to school. Yes!’” An anonymous participant remembered similar encouragement from a colleague, who said, “Don’t give up! You have a right! You are a woman, and you have a disability, yes, but you are still a human being, and you have a right to go get education. You can do it!” Melba attributed her confidence and success in

large part to her parents: “I think that everything in my life began since I had two aware parents who always insisted on telling me a very powerful phrase, which is, ‘You can.’” Nandar shared many encouraging words from her parents and declared, “They are very good parents. Without their encouragement, I couldn’t do anything.” Nathalie attributed her confidence to her mother and uncle, reflecting, “I had a lot of encouragement from my mother, and my uncle supports me a lot, too.” She repeated her mother’s words “You can do this. You can do that. You can do it.” Nisha expressed gratitude for her sister, whom she described as guiding her when she has delusions: “She says, ‘Go. Go. If you fail, it’s okay. If you pass, it’s okay.’”

The stories that participants shared about supporters who encouraged their personal authority also factored strongly into their identity stories. Charity lauded the social workers who encouraged her to leave the house and to connect with other survivors with psychosocial disabilities; she credited them with sparking her activist identity. Lizzie valued her mother’s encouragement to trust in her decisions about how and when to disclose her disability and appreciated her husband’s playful persuasions to use her crutch in public. Balkissa shared her immense relief upon going to live with her grandmother, who allowed her to leave the house and who supported her enrolment in a school for the Deaf. Atika and Maryana commended their parents for giving them freedoms within a traditionally restrictive society. Nandar esteemed her parents for teaching her independent living skills and for encouraging her to attend university in Thailand. Maru’s mother promoted Maru’s sovereignty by urging her “to keep on studying and to do more things.” Among others, Fatima cited the encouragement of leaders in her church. “They came into my house and encouraged me.” Last but not least,

Atika and Sona both cited their families' encouragement as emboldening them to travel outside their countries to attend the WILD program. "I am here because my parents have faith in me."

Imparting opportunities was another way that people encouraged participants to realize their potential. In discussing her activist identity, Maru spoke about the woman who introduced her to the Society of the Blind. Balkissa told a story about the man who first informed her and her grandmother about the school for the Deaf. Hen appreciated how her boss at Nowzuwan gave her a job and complimented her work over the years. Gloria described how her teacher first invited her to participate in physical education by marking the long jump distances for her classmates, and Mayette shared how Ma'am Venus recommended her for a number of training opportunities abroad.

In describing the empowerment journey, participants often outlined their experiences of applying for scholarships, WILD, and other training programs, and they made a point to acknowledge the people who first told them about the opportunities and encouraged them to apply. "I guess a particular organization that I joined saw that I had potential, and they immediately exposed me to different training opportunities." "People were saying, 'Hey, you should be involved.'" "They gave me the information, 'You should apply for the scholarship because you're very person[able].'" "He sent me a link of the details, and he said, 'Oh, why don't you apply for it? I feel that it is relevant for you, and you have really excelled in your work.'" "They encouraged me, 'You should apply for this program. You are perfect, and I'm sure that you will be selected.'" "Everybody was saying, 'You have to come [speak] to my women. You have to come to my group.'"

*Direct assistance.* Participants also benefited from receiving direct assistance in pursuit of their goals. Nandar explained,

For example . . . I cannot go up and down the steps very easily because of my disability. . . . If you are a nondisabled person in our society and you give your hand to me, then I feel a lot of confidence and I can easily step up and down. [If you're] not holding [me] very tightly—only holding my hand—it's very spiritually empowering. It gives me a lot of confidence . . . when I feel somebody is beside me.

Mbalu laughingly said,

[My] close friends are men, strong men with muscle, and if you don't have muscle to carry me, I'm not your friend [laughs], because at the end of the day . . . [I need someone] to carry me . . . up and down those steps with my chair.

Participants appreciated the direct and active involvement of other people in the form of financial aid and resources, of shared knowledge and skills from teachers and role models, and of advocacy efforts from their supporters. Like encouragement, participants often (but not always) interpreted such direct assistance as demonstrating that other people believed in them, particularly when the assistance was aligned with their needs, preferences, and goals.

Financial assistance was an important support, especially because financial barriers and limited resources were topics of concern for many participants. Thus participants made a point to acknowledge with gratitude the people who offered them material support.

Each area I would go, there were good people there. . . . When they noticed I didn't have food, they would give me food. I didn't have clothes, and they would give me clothes. . . . They saw that I was walking the streets, and they welcomed me into their homes.

Mbalu expressed appreciation for her relatives who paid for her to go to college, even though they did not believe she could manage all of the barriers. Balkissa described

having a financial safety net: “If I need something that costs a serious amount of money or something, then I’ll ask my brother and my sister, and they’re very generous to support me if it’s something that I really, really need.” Charity explained how starting up her organization took a community effort. “Everybody contributed to get some of the papers . . . and some little things to use [in the office] like pens and pencils, a computer. . . . Someone gave us a room to work in.” In the midst of experiencing harassment from her previous boss, who prohibited her from leaving the office or using a computer, Melba encountered a coworker who was willing to lend her a computer on the quiet. “This woman had fourteen computers that she was using to train children with cognitive problems. . . . She was not using all of them, and she lent me one of them. . . . All my work depend[ed] on that computer.”

Participants also recognized the various organizations that helped fund their work. “I’m happy to tell you that the Channel Foundation, they donated to us.” “The United Nations Population Fund gave funding to us every single year.” “We received [some funds] from UNESCO Korea just to do some little things.” “Recently, we had some little funds from the VSO UK. This is where I got some of the money to do my research.” “Last week I had a meeting, thanks to my dad, with Ford Foundation, and they’re going to be funding my project. They’ll start small, but it’s a good step because Ford Foundation is a big NGO.” “I have got a 3 million pesos project, which is the rehabilitation center for children and young adults with disability. . . . These are all funds coming from the national government agencies.”

Participants spoke about the teachers and role models who supported them directly by imparting informational and practical knowledge. Nandar appreciated her



mother for raising her with the expectation that she was perfectly capable of learning how to cook and do the washing. An anonymous participant shared a similar recollection.

I learned these activities [i.e., independent living skills] when my mother was alive. She was not looking at me like someone who doesn't know how to do anything, or she was not keeping me like an egg. When it was time to go to the field, she would say "Let's go." When it was time to sweep, I was the one sweeping, doing this and that as I grew up.

Hen talked about her braille teacher who shifted her understanding of what it meant to live with a disability and influenced her return to education. "Still now, one teacher keeps in touch with me always. Always he calls me, and everything he wants to know, and [he gives me a] lot of support." Maryana mentioned a friend who first helped her identify when she was being tokenized, a skill that she developed as she increased her awareness of audism and developed her activist identity. "My friend, who was more aware, said, 'Oh no, that organization . . . they're just trying to use you. They're just taking advantage of you, holding you up as a token Deaf person, just so they can get funding.'" Maru described how meeting another woman with a visual disability when she was 12 had a significant impact on her life path. She explained what she learned from her role model:

She told me . . . "I read braille." . . . She walked on her own. She took public transportation on her own with her cane, and public transportation is not accessible at all. And she cooked by herself. All of the activities in daily life, like cooking, doing the ironing, cleaning the house. . . . Later on, she got married, and I always asked her, "So how do you . . . take care of your kids?" We always either went to her house or she came to mine, then I could see how she could do different activities. I said, "Oh wow! I want to do that too." . . . [Even now], I'm always asking her for advice.

Participants also referenced the people in their lives who jumped into inaccessible or barrier-strewn situations to advocate with them or on their behalf. Balkissa appreciated her sister's efforts to locate a sign language tutor for her and to pressure the school for the Deaf to find a way to help her study beyond the sixth grade. Fatima attributed her ability

to go to school to the advocacy of volunteers from Leonard Cheshire Disability. “It was the efforts from those volunteers [that led to] my dad saying that, ‘Okay, Fatima can go.’ And I was so free at that school.” Mbalu remembered the doctor who advocated for her to be brought to the military hospital after her gunshot wound and commended the head of the All Girl Association who fought for her right to remain in high school. “She was able to defend me that, ‘She did not do anything. . . . Why should you ask her to leave the school?’” Melba shared that the inexperienced, nondisabled man who took the position that she was rightfully in line to receive ultimately recommended that she replace him. “After six months, this new boss advocated for me. He stuck up for me, and he said that I was able to do the job.”

In their stories, participants almost always described advocacy on the part of teachers, colleagues, and loved ones as positive, but they occasionally articulated limits to the helpfulness of such assistance. Maryana described not wanting an unrequested recommendation from another disability activist because she wanted to be accepted into the WILD program based on her own merits not upon the people she knew. Mbalu asked her mother and sisters to stop helping her with some daily activities so that she could learn how to do them herself. During our first interview, Nandar described a mixture of gratitude and impatience at the continued solicitude of her family.

When I was young, they took care of me a lot and they worried for me a lot. With everything, wherever I went, there was at least one person who came with me and carried, and they would find my purse and things—whatever I needed. . . . [Now] I can go forever, but for them, they have not changed a lot. They still worry for me and they want to go together with me. They want to go so they know that someone can assist me. When I was young, I liked it because I didn’t have to be alone and I depended on them. For now, I don’t like it. I don’t need so much assistance, and I don’t want to wait.

*Love, acceptance, and respect.* Perhaps most of all, participants felt supported by experiences of being loved and accepted for who they were and of feeling respected for their work. Participants encountered love and respect from families, friends, teachers, and colleagues. This emotional support allowed them not just to manage barriers, but to find energy and motivation.

Love and acceptance were essential supports. Feeling loved and accepted by the people around them appeared to offer participants a sense of belonging and of being understood, which buffered them from the many environmental and attitudinal barriers that they encountered. Nathalie explained, “The [disabled] child needs . . . support and love to be able to succeed and to do well.” Maru made a similar comment: “I think that’s the key [loving support], and what [personally] helped me go on was my mother.”

Participants emphasized the primary role of families’ love and acceptance in supporting Deaf and disabled girls and women, including themselves. “I think that for support: first the family.” “Inclusion begins in the family.” “I also emphasize that it is crucial for parents to accept children with disabilities without hiding them and always support them.” “I think that having a family that loves you and accepts you whether or not you do something matters. It helps you have confidence in yourself. I believe that that helped me.” “For me, my family, my parents give me a lot of spiritual empowerment.” “I have sisters and a brother. They always say, ‘We will not let you down.’” “[My siblings,] they are so, so, so proud [of me]. ‘You see how we have our sister? She’s very strong.’” “My family gives me strength. If a problem comes up and I’m not feeling really good . . . my family knows it right away. . . . They know me . . . and they help me feel so much better.” Many participants described the love and acceptance they experienced from

certain family members—including parents, siblings, grandparents, uncles, aunts, cousins, husbands, and in-laws—in terms so meaningful that family members factored into participants’ empowerment stories and into the development of their identities.

Many participants shared about the support they received from loving friendships. In discussing her closest friends, Hen reflected, ““Still now, we are friends, from class nine to now. Yeah, they are very big relation[ships in my life]. . . . I love them.” In addition to her family, Sona explained, “I have some good friends and family friends who are also very supportive of me and my work.”

Some participants mentioned appreciating the constructive support they received from friends. Nathalie said, “I have friends that I’m close to whom I learn a lot from.” Mayette described turning to her friends when she wanted honest feedback.

When I have a speaking engagement . . . after that, I will go to my friends and say, “How did I deliver my message? . . . I want your comments. . . . Tell me mistakes that I’ve done, how my projection was, how my eye contact was.”

Their friends supported participants by distracting them from difficulties as well. Gloria described coasting through complex emotions with the help of her social life. “I used to make friends with everybody and be quite social, enjoying my life, going out, and all these things. . . . So I didn’t know [at first] that this [discrimination] thing was really affecting me internally.” Charity said something similar about finding comfort in friendship. “It was fine [I didn’t mind the barriers] because I made friends, so many friends.”

Participants also underscored as meaningful the love and acceptance they experienced within their communities. Fatima, Hen, and Mbalu spoke about the love and kindness they received from some of their teachers. Lizzie identified acceptance as an

important quality that she sought in a potential life partner: “For me, my biggest thing was to find someone that would accept my imperfections.” Charity appreciated the emotional and spiritual support that she received from church leaders. “The pastors, I think they are counselors in themselves. . . . They are ever with me.”

In addition to treasuring the love and acceptance that they received, participants cherished the moments when other people communicated appreciation and respect for the work that they did. “This [disabled] girl’s mother asked me whether she could hug me. And she did, she hugged me, and she started crying.” Melba, in particular, drew a lot of strength from people’s expressions of gratitude and respect.

Sometimes it’s the mother of someone with a disability, sometimes it’s the person with disability, and sometimes it’s a civil servant or a politician. For example, the last speech I gave, the last conference I went to was . . . a few days ago. And when I was done, I was running to the airport to go back to Mexico City, and a teacher ran after me, a special education teacher. And he said to me, “I have been a special education teacher for ten years, and I have never understood disability matters the way I have understood them when you explained them, so thank you.” And then all the tiredness I felt went away, and I didn’t care anymore that I was only going to be able to sleep for two hours before [my next trip].

The depth and breadth of respect that Melba inspired in her community, not only strengthened her, but became the factor that finally silenced her abusive boss. She explained,

There was an event, and the governor’s wife was there. [My boss] had ordered me to be at the very back of the room where nobody could see me, but by chance, a journalist came through there. . . . He approached me and started talking to me, and then other journalists came over to chat with him. And so this journalist was flirting with me and wanted to introduce me to the others, [but] a newscaster there told him, “Don’t you know Melba? She’s been working for the rights of disabled people for many years.” And while all this was happening, they had microphones and cameras, and so my boss thought that I would be able to talk to the media [about him]. I was talking about simple things, but he saw from afar that I was talking to the most important TV channel in the country, so he never harassed me again, never harassed me again.

Participants appeared to benefit from the respect and positive reputation that they gained for the work that they did. Gloria said, “There are a lot of people who actually look upon me for support and learn from me. People around me . . . they openly tell that to me.” Charity declared, “The whole of my country knows how I’m working, and, at least, everywhere I can knock and get what I need.” Hen shared with a smile, “It’s my pleasure, in Bangladesh, everybody who is working with disability, they know me.” Sona stated, “In Côte d’Ivoire, everybody knows me and what I do. I’m very active there.” Nandar spoke about the respect shone toward her organization: “[People] pay respect to our disabled people’s organization, and they communicate [this]. . . . They pay respect to our suggestions.”

In describing the empowerment journey, participants mentioned the honors and awards that they earned along the way. Gloria received the “MALALA award for being the best supporter of the differently abled.” Mayette recalled how good it felt to receive awards in school and feel her grandmother’s pride in her. Mbalu remembered receiving a “prize of perseverance” in high school, which prompted her teachers to recommend that she come to stay on campus in the boarding home. In addition to winning scholarships for school, Nandar attended a community development and civic empowerment training at Chiang Mai University in Thailand, where she won the first prize for a project that she proposed to foster inclusive education and community awareness in Myanmar. The funding support that she received as part of this prize helped her to found her DPO, the Exponential Growth Organization. In our first interview, Bárbara shared about two awards that she had won and how they motivated her work.

I have also been honored with two very important awards in my country. Last year I was awarded the prize for women who had overcome adversity, which is

given by the Ministry of Women and Disadvantaged Populations. This is the highest civilian honor awarded by the State and is part of a group of awards for women, with the selection process involving worldwide participation. . . . The second award was given to me by the government of Lima, my hometown, in the category of Social Work and Disability for promoting human rights for people with disabilities. While the award is certainly a personal motivation, it's also a commitment that I have with my brothers and sisters with disability, who, for example, support my ideas and support my work.

Some participants reported an increase in the respect they received after traveling to the United States for the WILD program. Mayette explained, "Stating that I have been in different countries, especially in the USA, helps me . . . in getting support and funds from the other offices." Fatima said,

In our family . . . I'm the first one to travel. . . . My dad is proud of me. He's so happy that I've traveled—even my mommy. . . . The other thing that has been different to me is that I'm now famous. . . . As of now, my community has started responding to my views. Whenever I say something to the people who are not disabled, they welcome my ideas, just because now they know that "Fatima is a leader. Fatima can do anything, and Fatima knows how to challenge herself." . . . Yeah, they are now calling me "That Fatima American lady."

Lizzie described a similar phenomenon: "It took going to WILD for people to say, 'Oh look at Lizzie; she can actually do something.' An outsider had to recognize me and my efforts for them to say, 'Oh wow!'"

Finally, Charity offered an intersectional, multisystemic example of the material and emotional supports that she believed benefit people with psychosocial disabilities:

In my experience, people with psychosocial disability . . . when you keep the relationship with your [qualified] doctor, [have access to and] take medication in a proper way, have your friends around—not keeping to yourself in a place where you are alone—you do better. . . . I think nothing goes wrong.

### **Reflecting on the Journey**

In summary, participants described venturing forth on life-long journeys of empowerment. "Slowly, I developed myself, and I became a leader in my area." "This is not a race wherein you have to be the first. You have to go slowly but surely." They

appeared to orient to the constellation of education, awareness, and skill-building, which guided the course of their journeys. They manifested their orientations to awareness by highlighting moments of awakening in which they became newly aware of key aspects of their realities; by expressing strong desires to learn; and by pursuing formal education, training opportunities, and travel experiences. Along the way, they surveyed both internal and external landscapes, noticing changes in their self-awareness and in their awareness of their social ecologies.

Participants placed great value on the inner landscape of self-awareness. This quality of self-awareness was profoundly evident in their identity stories. Additionally, self-awareness arose in their descriptions of empowerment when they discussed their individual strengths, such as their interpersonal, organizational, or motivational skills, and their environmental advantages, such as financial resources, accessible facets of their surroundings, or education and employment experiences. In expressing self-awareness, participants shared their desires, hopes, and dreams, which included increasing their knowledge and skills, finding life partners, securing paid work, acquiring important material resources, becoming leaders, and effecting social change.

Participants honed their awareness of their complex social ecologies, as well. This awareness included a recognition of the many formidable barriers that Deaf and disabled women experience across the world, as well as the interpersonal supports that sustain and strengthen them. Both barriers and supports played significant roles in participants' depictions of their salient, intersecting identities and in accounts of their empowerment journeys.



Participants discussed environmental barriers that they encountered personally and witnessed as part of their activism work. Specifically, participants identified the need for increased knowledge and skills in their personal lives, among Deaf and disability communities, and within the greater hearing or nondisabled society. They identified communication and information barriers that existed in the lack of sign language interpreters, in inaccessible printed information, and in physically inaccessible libraries and classrooms. Physical access barriers included curbs and stairs, inadequate space for wheelchairs, and print signage, all of which rendered disabled people immobile in their own homes, the homes of neighbors and friends, public spaces, schools, workplaces, medical centers, public transportation vehicles, and voting centers. The lack of accommodations, such as extra time, physical assistance, and adaptive technology, interfered with Deaf and disabled women's participation in school and workplace environments. Financial barriers and limited community resources hindered access to education, healthcare, prosthetic devices, personal assistants, sign language interpreters, braille materials, adaptive technology, and adaptive sports. Many participants described being unable to find paid work, particularly in the social sector, and struggling to raise funds for their activist organizations. Restrictions and barriers to personal sovereignty kept Deaf and disabled women from leaving their homes, exploring their communities, accessing education, getting married, seeking help from police, expressing themselves, voting, and running for political office. Participants especially emphasized the wide-ranging harm caused by emotional, physical, and sexual violence, which brought about injury, disability, and illness; perpetuated isolation and confinement in the home; and further restricted access and participation. Last but not least, participants described

negative attitudes and social stigma as presenting significant barriers to Deaf and disabled women and girls from the Global South. The types of barriers that participants described all intersected and interacted with one another and spread adversity to every level of the social ecology.

The types of interpersonal support that participants highlighted as helpful in sustaining and strengthening them included encouragement, financial and other forms of direct assistance, love and acceptance, and professional respect. Specifically, participants appreciated the encouragement they received from family members, friends, teachers, and colleagues who offered encouraging words, promoted their individual sovereignty, and shared opportunities. These forms of encouragement gave them the message that other people believed in them and in their abilities to realize their full potentials. Participants also acknowledged the benefits of direct assistance, describing the people who offered financial or other material assistance to support them personally or professionally, the teachers and role models who had a positive impact on their lives, and the occasions when people used their male, white, hearing, or nondisabled privilege to help them advocate for equity and access. For the most part, participants alluded to such direct assistance as helpful, but they occasionally identified limits to its helpfulness when the assistance was not aligned with their needs, preferences, or goals. Finally, experiences of love, acceptance, and respect appeared to be especially meaningful forms of support. When they felt loved by their families and communities and accepted for who they were as whole people, participants seemed to develop a sense of belonging and strength that buoyed them during times of adversity and exclusion. Participants also cherished instances of professional respect, highlighting moments when their colleagues and

members of their communities thanked them, praised their effectiveness, presented them with honors and awards, and welcomed their suggestions.

Overall, as participants shared their perceptions of the empowerment journey and their understandings of the barriers and supports experienced by Deaf and disabled women and girls, they expressed a sense that their organizations, communities, and countries were making gradual progress. Participants who started their own organizations described their organizations' continuing growth. "In 2009, I sat down thinking about that organization, and it is now growing little by little." "Step-by-step, I go forward to extend my organization and to extend the opportunities for people and children with disabilities." "We are making progress." Participants expressed a similar sentiment when it came to their communities and countries. "Persons with disability are very happy that most of the laws are now little by little being implemented." "It's improving bit by bit." "It will take time. It doesn't mean like one, two days. It will take . . . ten, twenty years—I don't know whether I'll be here or not within ten years—but [the youth] are going to make changes." "A little bit of change is coming in our culture." "We're getting there. People are beginning to hear our voices, so you know, we're getting there slowly but surely."

Participants' sense of systemic progress appeared to correspond with their personal sense of growing empowerment. Gloria reflected, "What I have gone through in life has brought me to this place and status. If I am empowered today, it is because I was disempowered before and didn't even realize much that I was in that state." Mbalu made a similar comment about deciding to persist in the face of barriers: "I made up my mind that it's better for me to suffer whatever I have to now and, in the future, be empowered."

Hen said simply, "When I see my past, I was afraid. When I see my future, I am powerful." These declarations of progress and power among participants emerged more fully as components or manifestations of empowerment, which is the topic of Chapter VI.

## **Chapter VI**

### **Results: Manifestations of Empowerment**

Chapter VI presents the ways that participants manifested empowerment within themselves and in the world. The chapter begins with an overview of the intentional approaches and strategies that participants used to cultivate a sense of empowerment in their lives. These approaches included orienting to their values, working hard, and allowing space for life's challenges. The chapter then reviews the ways in which participants manifested power within themselves, namely by feeling confident, making decisions, and fostering relationships and a sense of community. Next, the largest section of the chapter reports the many actions that participants took to build inner strengths and to pursue self-advocacy and social justice. Participants' collective or collaborative empowerment was an important part of many of their experiences, as well, and thus examples of their power with others appear all throughout the chapter. Chapter VI ends with an integrative section that summarizes the chapter, reflects on the role of empowering contexts, and shares participants' observations about the connections between empowerment and identity.

This chapter supports and elaborates upon many of the themes begun in participants' individual identity stories (Chapter IV) and in the general survey of participants' empowerment journeys (Chapter V). Identity and empowerment appear to be shifting, multilayered, interrelated constructs. Thus in order to get a fuller picture of how participants manifested empowerment in their lives, the reader may need to refer to all three results chapters in combination.

## Personal Approaches to Empowerment

As participants discussed their empowerment experiences, they described their personal strategies and approaches to cultivating a sense of empowerment. Maru explained, “You have to . . . look for strategies that will help you survive.” Their methods for fostering a sense of empowerment set the stage for many manifestations of empowerment in their personal lives and activist roles. In addition, these approaches arguably represented manifestations of empowerment in and of themselves.

**Orienting to values.** Participants’ tendencies to orient to their values appeared to guide their approaches to and strengthen their experiences of empowerment. “My sense is that people should try to work on their own values.” “If I don’t have values . . . then there’s nothing that can be done or changed.” The value of education, for example, was a guiding approach to empowerment because it offered direction to participants’ personal and professional journeys. Education/awareness also contributed to empowerment because the more educated and aware that participants felt, the more empowered they perceived themselves to be. Other values, including God/religion, family, and social justice, arose in participants’ stories as approaches and contributors to empowerment.

***Faith in God.*** Many participants referenced faith in God as an orienting value. “I believe Allah. He’s everything.” “God has given me everything, and now he’s testing me with these problems . . . whatever he has to do, I’m ready. Whatever happens is for good because God is never wrong.” “God created this day a long, long time ago, and we have managed.”

Participants turned to God as a strategy for seeking guidance on the empowerment journey. “I ask God a lot to guide me.” “What motivates me, what inspires me . . . is my

relationship with God.” “God leads me in many ways to do many things. God helped me to develop in my education. God has led me to [travel to] many places that I never dreamt I could get to.”

In particular, participants discussed how their faith in God directed their activism work. For example, Bárbara cited her conversion to Evangelical Christianity as the event that led her to become an activist. Melba explained how her spiritual philosophy, particularly her belief in an interconnected universe, helped shape her activism work:

There are some guidelines that are the basis of what I do, and those guidelines are based on spirituality. . . . I learned from reading different texts that . . . we are all a part of the same. We are all one. So everything I do is going to affect or benefit everybody including myself. So for all of us to be better, we all have to do positive things.

In addition to guiding their activism work, faith in God appeared to offer many participants the strength to do the work. Atika observed, “When you start something with a good thought—doing for the betterment of others—God helps you.” Charity reflected, “The Christianity can give you the power to support other women.” Mbalu said simply, “I draw my strength from Christianity.”

The strength that participants derived from their faith often manifested as a sense of purpose. In her identity story, for example, Mayette explained that she had the strength to flout social expectations and joyfully adopt her multiply disabled son because she believed that parenting him was part of God’s purpose for her. Many other participants expressed similar sentiments. “I believe that where God has put me, I am supposed to be.” “I know God uses me as His instrument.” “What keeps me going is . . . knowing there’s a higher being or a superior being, knowing that there is a God . . . and that I’m not a random creation, that I have a purpose.” “God made me with a purpose, and He

created me to be a leader.” “I have faith in God, and I know God works miracles, and he can work miracles through me.”

I was put on this earth for a reason, and as much as things don’t go right sometimes, it’s [meant] for you to hold onto whatever faith you have, and trust that God has good plans. . . . So it’s for you to be resilient and just hold on, whatever will get you through until those plans come to fulfillment.

***Family.*** Participants oriented to values of family to guide their pursuits of empowerment and to fortify them with a sense of strength. ”I feel blessed to have a family.” “Because of my son, I will do everything.” “I have to be better for my daughter! She needs, she deserves a strong role model.”

The values that participants placed on family guided their choices about how to pursue empowerment. For example, in their identity stories, Bárbara and Mbalu cited their fears of becoming a burden on their families as impelling their pursuit of knowledge and skills. Nandar shared how her family’s perspectives and opinions guided her educational and career decisions. Lizzie explained that her desire to be available for her family prompted her to start up a disability consultancy out of her home.

Mayette explained how her orientation to family and faith—the intersection of her valued identities as mother and Catholic—shaped and guided her choices as a professional and activist:

From Monday to Friday, I have work in my office, and Saturday, sometimes I have a meeting with my organization. . . . [On most days,] from eight to five, I’m in the office. . . . As I have said, I have an adopted son who is a special child . . . so I see to it that I have to go home by six so that I have time to become his mother, to give him dinner and change his clothes before going to bed, and make him asleep in bed. . . . On the following day, I have to leave the house at seven or seven thirty . . . [and] before going to my office, I have to feed him and see to it that all his vitamins are ready to be given to him. . . . [Each] Sunday, I have to be with my family. . . . Every Sunday, we have to go to church.



Participants cited their family roles and relationships as contributing to their inner power. Maru and Rose-Ann, for example, indicated that much of their inner strength derived from their experiences of growing up within families of women. Melba, Nandar, Nisha, and Rojanet attributed their inner confidence to the values that their families taught them. Lizzie pointed to the moment that she became a mother as the moment that inspired her acceptance of a disability identity and shared how her family roles gave her a sense of purpose:

For me, I feel that [being a mother] is my purpose! And then being disabled and owning my disability, it just fits! Being a wife and a mother and being disabled, it's just right. It's very empowering to be able to be all three.

***Social justice.*** Participants developed social justice values that appeared to guide and motivate them. Maru observed,

There is much injustice and much inequality in the societies of our countries. . . . We ourselves shouldn't wait for others to do something but should defend and break down barriers of discrimination. Generally, this is what I think, and it helps me to continue to fight.

Rose-Ann expressed her hope:

I just want to be able to say that, for those persons with disabilities [who come after us], they know that they will not have to fight the fight that we fought. The world might be a bit smoother for them, and I would hope that . . . they [will, in turn,] continue to fight.

Some participants developed social justice values after surviving or witnessing adversity. Nisha explained, "I started to meet people with psychosocial disability. . . . And then I felt that I had a responsibility to do something for those poor people who are like me." Atika shared, "If I'm facing a challenge, I have to do something productive. . . . I must do something for others so that they don't cry like me." Mbalu reflected,

When I was in college, I started putting things together that I'm going to get on an organization that will be advocating because of what I have come through. I was

strong to survive it, but there are others that can't survive it, so if there's a way that I could be able to make a change . . . that will cause others to benefit from what I suffered . . . let me be the one to make that change.

Participants also described how experiencing or witnessing positive changes strengthened their commitment to social justice. For example, organizing her first successful Christmas party and witnessing the joy that the children experienced gave Melba a sense of purpose that launched her activist career. When Nathalie was able to teach a mother and father how to care more lovingly and effectively for their multiply disabled, eight-year-old daughter, her feeling of success helped renew her dedication to activism work. Mbalu cited the stories of black civil rights leaders and the changes they made as inspiring her work:

[In school] I read politics and history . . . from different parts of the world. We did a lot of Martin Luther King. We did something on Booker T. Washington . . . Nelson Mandela. . . . We did all of these black people who were fighting for their rights and freedom, and when I do read those things, I always have it in mind that . . . these people fought . . . for independence, and they have it. We have the same rights. . . . If I and other people can have the power to . . . make it right . . . work it out, then I believe it will work out. So those people have always been my inspiration.

Prevention was one of the social justice values to which participants oriented. Lizzie said, "I feel it's important, if you want to help, then start at the root, the cause. Don't try and just fix the problem, but find out what caused the problem to begin with, and try and get it from there." Participants' emphases of education and awareness throughout their empowerment journeys exemplified their high regard for prevention. Rose-Ann reflected, "You have to think to yourself . . . have you given all you can to make this world a better place? Have you given all you can to build awareness?"

Participants also drew upon a social justice value of human diversity.

Each and every person has a disability [body-mind difference] without realizing it. . . . You might not realize that you [currently] have a disability, or one day, you may form your disability. . . . In a bus or driving . . . maybe you could be in an accident . . . [and] you may cause disability [in yourself or others].

For example, in defining her identity as a differently abled person, Nandar outlined her thoughts about human diversity. “I have different abilities, [just as] there are little differences within nondisabled people. . . . Every human being has their own physical identity, so we need to accept their identities.”

Charity explicitly connected human diversity to the importance of entertaining a complex definition of empowerment:

I think when we say empowerment or development, we have to think different things. . . . Let’s say if we talk about women with disabilities, they have [or include] different groups, and they have different challenges. How am I going to empower them? How are you going to empower these people, having different challenges?

The value of inclusion, especially in the context of human diversity, was another value that participants identified as important to social justice. “We are human. We are children, and we are women, so we need to be included.” “Inclusion, inclusion, inclusion, we need to be included! Nothing about us without us!” Melba shared how her philosophy of human diversity and inclusion directed her professional approach. “That’s another tool to do my job—understanding that we’re all part of the same whole but also understanding that the other person is going to be different from you, and you have to respect that, then promoting inclusion.” Nandar founded the Exponential Growth Organization specifically so there would be an inclusive organization that addressed the concerns of a cross-disability population. In describing her choice to be a for-profit disability consultant, Lizzie observed, “A huge population of our world is disabled or is going to be disabled because of age . . . [so] It makes business sense [for my clients] to [learn how to] cater to

the disabled.” Bárbara said, “If I ever become a congresswoman, I will work to improve the conditions of people with all kinds of disabilities.”

**Working hard.** Once participants identified their guiding values, many employed a strategy of working hard to pursue those values. “You, as a person with a disability, have to be ready to put in the work.” “There’s a lot of work day after day.” “I’ve been working very hard.” “I am accustomed to working a lot.” “I keep myself very busy, very occupied.” “I won’t stop my work. I won’t stop my studies. I won’t stop again in life.” Specifically, they discussed the need to plan and prepare, the strategy of expending extra effort, and how being a hard worker factored strongly into their identity and empowerment stories.

**Planning and preparing.** Participants used strategies of planning and preparing to facilitate their participation in social and professional environments. “I have to plan and make sure that, for instance, say that I’m going out, what kind of distances I will have to walk, that kind of thing.” “I’d get up at five to get ready for half seven class or eight o’clock class.”

If I need to go to work early, I get up early and I’m getting ready before the time. I’m always on time. . . . I know I’m a slow walking person—I’m not walking very fast—so I need to prepare step by step. If I need to go to work [in the] early morning, I prepare my clothes on the table for tomorrow morning, and I already put out my document, my fare pass. I’m all ready for tomorrow before I go to sleep.

**Expendng extra effort.** Participants explicitly adopted the strategy of working extra hard as they pursued empowerment. “You have to really push yourself.” “You immediately begin working and start to work, work, work. There is no time to rest your body.” “My responsibilities . . . I have no time [within] 24 hours.”

One environment in which participants described expending extra effort was at

school. “When I would go to school, my parents would always say, ‘You have to make a little bit more effort than the others so that your teachers understand the importance of giving you an education too.’” “I used to stay behind, and I’d just be in the class and start doing my homework . . . do all of my studies . . . [while] people and other friends were having fun.” “[The other students] did not work hard, but I work very, very hard.” “I want you to know something. The efforts that students use for a whole week are the [same as] I’m using for a day.”

Just navigating the many access and information barriers in the education system involved considerable effort. The Deaf participants, for example, discussed the hardship of pursuing their education in the face of oralism or without sign language interpreters in the schools. “The teachers didn’t sign; they just talked all the time.” “All through university, I didn’t have any [sign language] interpreters.” Physical access barriers also caused exhaustion and stress. “All my classes were on the third and fourth floor. So I can’t remember how many times I fell down the stairs.”

I took a lot of risk going up and down those steps with my [wheel]chair . . . and at times . . . I did get tired, lifting up all the time and . . . putting on trousers, dressing like a man all the time because they had to be lifting [me] here and there.

Participants also dedicated extensive time and energy in their work environments.

When you have a disability . . . you have to work two or three times as hard and prove yourself two or three times as much as people who do not have a disability to show that you can do the job. But if you’re a woman [with a disability], you have to prove yourself four or five times as much.

My performance used to be always on the top level in all the organizations I worked for, and they never used to have any regret of recruiting me or any regret of having me in their office as a team member because I used to stretch beyond my limit to do my job.

“We with disabilities, we are really something else. We see people getting to it. We see

people going to conferences, we see people doing this, but never do we see the work that people put into it.”

Those participants who were fortunate enough to have paid work often found that much of their activism took place outside of the work day. “Since I am a full time worker, I am not able to give enough time for some programmes related to the differently abled . . . [so]: I am trying to give all my personal time.” “I do voluntarily so much [activism] work . . . after my own work.”

I just say to myself, “You have to develop a time management schedule so that you do this at home but still give 100% when you’re at work.” So initially . . . I had to do a lot of work at home which pertained to the [activism] project. . . . It was difficult at first.

***Hard worker identities.*** Working hard was so important a strategy to participants that challenging themselves and persevering were qualities that surfaced in many of their identity and empowerment stories. Maru stated, “What I think is important that you know about me is that I’m a person who doesn’t limit herself.” Lizzie shared, “I told myself, ‘I will stop picking activities based on what’s comfortable for me.’” Mayette said, “My description as a woman with disability is a strong woman with determination. I always face my challenges with no regret.” Mbalu said of her fundraising endeavors, “I keep on pressing. . . . I’m so, so stressed . . . but I’m still trying.” Nandar explained, “If I don’t try for the best, I cannot be the master of anything. Rose-Ann declared, “I want this experience to really stretch my limitations. . . . Although physically I may not be able to do it, I push the limits.”

**Allowing space for challenges.** As they approached empowerment, participants also allowed life’s difficulties to happen. “I have to recognize this problem, and I have to get along with it.” “You know, I just took things as they came because that was the only

way I knew I was going to survive.” Specifically, participants discussed their strategies of adapting to, accepting, and even embracing the aspects of life over which they had no control.

***Adapting.*** Participants managed to adapt in profound ways to systems and environments that often neglected and excluded them. “Life makes you change.” “The most difficult part of any situation is the first time [that you encounter it], but as time goes on, [the difficulty] has to resolve itself, and you’re better able to deal and to handle it.”

The ideal, and what we want to achieve, is that the environment be the one that adapts itself . . . but unfortunately, until that happens, we are the ones who have to adapt to the environment that is not accessible for us.

One way that participants adjusted was by using adaptive devices and technology, such as white canes, crutches, walkers, wheelchairs, and screen-reading software. As part of her identity story, Mayette referred to her crutch as her “second husband.” As we walked on the uneven sidewalks and noisily trafficked streets of Cuenca, Maru happily shared tips for using our white canes most effectively. Rose-Ann spoke about her experience starting to use a rollator.

That year was the first year that I was introduced to the rollator, a walker with wheels. Usually, I’m a very proud person, but I’ll tell you this, it took nothing out of me to begin to use it. . . . It gives me a lot of independence to get around . . . so I accept it and embrace it as a positive. . . . Now if I can embrace this piece of equipment, what else can I embrace in life?

Participants also adapted to their circumstances by devising creative solutions to problems. Charity spoke about how creative problem solving played an important role in running her organization.

As a leader, you know, you have to be creative. . . . Maybe you get someone’s friend’s vehicle and take her to the hospital, talk to the doctor using the telephone and get some ideas from him . . . many different ways of overcoming those

[transportation and informational] challenges.

***Accepting and embracing life.*** Participants often expressed acceptance as a useful approach. “I think [we are] women who were made to be who we are.” “I started by trying to accept people for who they were, no matter what.” “I just accepted it. ‘Well, it was the will of God then.’” “I just decided, ‘Okay, I’ll deal with this. . . . I will just accept it and go along.’” “I just say, ‘Let these things pass. . . . So I don’t worry so much.’”

In their identity and empowerment stories, participants shared profound moments of practicing acceptance. Balkissa, for example, described accepting the fact that she was not able to attend university. “It was fine to get some education. It was okay. I got . . . what I could. I just kind of accepted things as they were. This is life.” Lizzie spoke about learning to accept herself over time and letting go of her desires to fit in. “I don’t have to impress or try so hard to fit in. . . . I don’t have to be friends with the whole world. . . . I have a few friends—one or two—and that’s fine.” Gloria described overcoming her fear of public speaking by practicing acceptance. “If others are talking about me, others are making fun of me, it’s their problem. It is not my problem. That is not going to affect me.”

At times, participants moved beyond acceptance to embracing difficulties and new experiences. “Every single day is another experience for me. Every single day, I learn something new.” “There’s a lot of learnings for me. Every day, there is something or the other to learn from each person, from each activity which we do.” “I’m always willing to try something new.”

It’s [about] how you are going to embrace what you learn. You could either embrace it or you could discard it. It’s up to you. I tend to try to embrace every disappointment, every success. . . . Every experience that is handed to me, there’s something to take away from the experience. There is something to learn . . . and I



intend to do it.

Adopting a positive outlook appeared to be a part of embracing difficulty. “I’m pretty optimistic in my life.” “I like to mix humor into my dealings with people.” “I’m just trying to look at the positive side . . . the brighter side of it, because you have to. You need this positive attitude for you to be able to stand up for other people.” “It’s interesting how, if you have a positive attitude, it changes how you look at things. It changes a lot.” “There is a song in Spanish that says, ‘Live happy now, while you can.’ . . . The lyrics are good.”

I try looking for the positive in anything, and when something doesn’t go how I want, then I tell myself, “You know what? Maybe this wasn’t the right time, and maybe I’m not even ready for the experience. It will come when I’m ready.”

As they embraced their life experiences, participants sometimes went as far as welcoming their failures. “Failure first before success.” “Let me try. If I fail, it’s not a disgrace.” “If there is something that makes me fail, I say that’s good. . . . I will definitely encounter the mistake early on the second time around. And I will be better if not the best.”

### **Manifesting Power-within**

Participants’ power-within shone through their narratives from beginning to end. “You have to be really dynamic in facing a lot of challenges. . . . You have to be strong enough to face them.” “You have to be able to pick yourself up, dust yourself off, and keep going.” “I’m well. I’m at peace.” “We are raising hope and strength.” Some manifestations of inner power that arose in participants’ stories include times when they felt confident, made decisions, and fostered relationships and community.

**Feeling confident.** Participants appeared to experience confidence as an important manifestation of empowerment. “I believe that it helps to have confidence.” “We should be able to move with the flow and be confident.” “People should have confidence in themselves, especially people with disability.” “It really has helped me to have confidence in myself.” “I manage to come through those challenges by being confident.” “If I lack confidence . . . and if I don’t know what my role is with regard to self-respect, then there’s nothing that can be done or changed.”

Confidence was a theme in many participants’ identity stories. Nandar said, “As you know, I have a lot of confidence.” Rose-Ann declared, “I am very confident about who I am . . . a confident, independent woman that is capable of operating all of her goals.” As she started to raise her awareness, Maryana found her confidence: “I thought, ‘I shouldn’t be so passive,’ and I started to become a little bit more confident and have more confidence in myself.” Over the course of her empowerment journey, Balkissa discovered, “I can make a difference, and I can be more than what my circumstances have limited me to.” Fatima proclaimed confidently in the face of attitudinal barriers, “It’s me, I’m Fatima. I know what to do. I know what not to do, what’s good.” In our second interview, Bárbara traced the evolution of her confidence and ended by saying, “Now . . . I am a more firm and secure woman in my decisions, and I don’t feel intimidated when I am invited to be a speaker and to explain a certain topic or to speak with authorities about disability.”

Some participants described discovering and tapping into an inner reserve of confidence and power that helped sustain them. As she discussed her drive to return to school after being injured in the war, Mbalu explained, “You build the confidence in the

mind. You empower in the mind. . . . So the thoughts came, and I empowered myself with them. . . . It all started with a message.” Nisha described a similar process as she studied schizophrenia, practiced nonattachment from her delusions, and focused on her life goals. “I believe anything and become strong.” As she pursued her empowerment journey, Fatima eventually came to believe, “Even though I’m disabled, I can do anything.” When faced with a challenge, Charity recalled thinking, “If others can, why not me? So that was like determination.” Melba described learning confidence, in part, by practicing skills, “I used to try many times to see if I could do something. I believe that this helps to have confidence.” Rose-Ann referred to her “Attitude that empowered me to know that I can do anything that I put my mind to.” Bárbara stated simply, “I motivate myself.”

Participants also cited their families as a source of their confidence. Melba said, “I think that having a family that loves you and accepts you . . . helps you have confidence in yourself. I believe that that helped me.” Nathalie referenced her mother’s encouragement as a source of her confidence. “My mother always says . . . ‘You can do it!’ and it really has helped me to have confidence.” Nandar ascribed the early development of her confidence to the empowering style in which her parents raised her—“There were a lot of advantages. . . . I could have self-confidence.”—and much of her continued confidence to her husband’s support—“I get success because of [my husband] and I have confidence.”

Education also appeared to offer participants confidence and strength. “It really has helped me to have confidence in myself . . . all the education that I’ve had and the different programs that I’ve had an opportunity to learn from.” “I have self-

confidence . . . [in part, because] I attended a regular school.” “Understanding of human rights of women with disabilities . . . this is where I got confidence.”

I took several classes related to women and to disability issues and human rights. As I learned all of this information, I just realized, “Wow, I am a human being! I do have rights! I am a strong disabled woman!” And it just gave me the inspiration and the passion to continue doing my work so that I can work and support other people who have disabilities and empower them in my country. So that fire was lit.

**Making decisions.** Participants appeared to experience making decisions as a manifestation of empowerment. “You have to take decisions.” “I think it’s important to feel like you can say no or you can say yes, that you have alternatives.” “You can do it. You just have to decide to do it.”

Participants valued their abilities and the inner strength that it took to make difficult decisions. “[I’ve had] some tough decisions, some regrets, some good decisions, everything in my life. . . . Whatever it is, in my case, I would be the decision maker.” “I am a . . . firm and secure woman in my decisions.” “Within my mind, I made up my mind.” “I am very clear in my decision.” “After I went through a lot of challenges, I made up a decision.” “I had to take a big decision. . . . It was a very difficult decision for me actually.”

They also recognized that their abilities to make decisions depended in part on the freedoms afforded them by their families and other social systems. “When you’re educated, you’re in a better position to make decisions for yourself.” “In the decision making, we have to listen first.” “I think I’m lucky because, everything I’m doing, nothing was forced upon me. I made my choices.”

The decision will be taken by me and not others. . . . Though my parents are there and I respect them . . . I would be the final person, the ultimate person to decide whether I need [something] or not. That has been happening in my life, and I want

it that way.

**Fostering relationships and community.** Participants described drawing strength from their relationships and from a sense of interconnectedness. “I have developed so many beautiful relationships.” “It’s always nice to stay connected.”

Families played a key role in participants’ sense of interconnectedness. In addition to describing the role that some families played in supporting participants and in building their confidence, some participants cited their sense of connection with family as providing them with an inner joy and strength. “I’m strong because of my family. My family is my strength.” “I have fun enough with my family.” “I’m happy with my family.”

Participants also described drawing strength from their friends. “At the end of the day, I will be calling my friends.” “I just have my friends nearby me.” Maru, for example, discussed drawing strength and nourishment from her social life. To Fatima, one of the most positive aspects of going to school was making new friends. “After [starting school] . . . I started recruiting up friends. A lot of people started becoming close to me . . . So the starting of my school made me change my life.”

In their identity stories, many participants mentioned the strength they derived from finding communities of other Deaf or disabled people. Charity spoke about the stage in her identity development when she found other genocide survivors with psychosocial disability. Maru enjoyed spending time at the Society of the Blind. Atika began reaching out to other disabled people after her accident, and Nisha found a community of people with psychosocial disabilities after graduating university and spending some time at home.

Their sense of connectedness to communities of Deaf or disabled women offered strength to other participants, as well. “We’re in this together.” “It can help if I can discuss it with my friends who have different disabilities.” “I think when you develop that community, like with my [WILD] sisters here, you become friends, and that feeds your inner strength.” “It gives me a lot of courage when I meet my sisters and brothers who are like the way I am, who are in the same disability as I am. . . . That’s where I get joy.” “Sitting with other different categories of disability, when they talk about their challenges, you start thinking, ‘Hey, there are others who are struggling also.’ . . . So we can’t lose hope.”

We were all equal in terms of disability—whether you were blind, whether you were deaf, whatever your disability was—we were just women with disabilities and we each understood each other’s struggle. That was the unifying factor, the strengthening factor.

### **Manifesting Power to Act**

Participants manifested empowerment through many of their actions. Maru said, “You have to move. You have to talk. You have to try.” Lizzie reflected, “You have to do something different [outside your comfort zone] for change to happen.” Gloria shared her belief that “If you want to do something and you want to be a leader, you just step forward, make the effort.” In describing her own leadership style, Sona said, “I make things happen, and I step forward, and I’m a go-getter.” Atika declared,

Women’s empowerment . . . means you can really do something. You are a woman, and you have to do something. You have to show the world what you are and what you can do. And that’s my idea of empowerment, to show everyone that you are the best, that you can do anything.

The two main areas in which participants manifested their power to act included practicing or building inner strength and pursuing self-advocacy and social justice.

**Acting to build inner strength.** Participants practiced a number of activities to build their confidence and overall fortitude. They took action to tackle the question of “how to develop expertise . . . to constitute an outer and inner strength, to work to address these challenges.” Specifically, in order to build inner strength, they actively engaged in spirituality, self-care, and traveling.

***Practicing spirituality.*** Participants took action by practicing spirituality to help build their inner peace and strength. “Our religion is Muslim . . . and we maintain it.” “I look for different ways to be always in contact with God.”

Many participants attended religious services to help build their spiritual strength. “I am very committed to going to church.” “I am a regular church goer during Sundays.” “We have a church nearby that’s close to our house, where I go.” “I mostly try to attend mass when I’m stressed, but I also go to meditation retreats.”

In their identity and empowerment stories, Charity and Mbalu spoke about the role that church played in strengthening their senses of empowerment and their survivor identities. Charity said, “When I go to church, this is where I find my peace.” In describing her church attendance after acquiring her disability, Mbalu said, “That was where I started to clear my mind again. I gained my capacity again, the self-confidence that I could make it.”

Participants also practiced their spirituality through meditation and prayer, which appeared to offer them inner peace and strength. “I’m still praying.” “I do meditation, visual meditations that strengthen the spiritual.” As with attending religious services, participants alluded to the importance of practice. “Every day, I can’t do anything without having a prayer. I can’t do anything without thanking God.” “I like praying so

much, yes. . . . I like praying, especially at home—in the morning, in the afternoon, and during night times.” “I have memorized all the chaplets that Catholicism has and doing the rosary.” One participant specifically mentioned the role of prayer in giving her the strength to make decisions. “I asked God for a sign.”

In her identity and empowerment story, Melba described engaging in an array of spiritual activities that strengthened her and gave specific examples of which practices helped her in which situations:

For instance, if I’m about to have a very difficult meeting, then I go on YouTube and try to find songs about the sacred heart of Jesus or about the virgin Mary, there is a song I play a lot that is sung by a nun, and she sings to God, and it goes, “Why am I afraid if nothing is impossible from you?” . . . If I know that I’m going to have a meeting in which there will be barriers that I have to overcome, I sometimes also play . . . a song to Ganesha, a [god] from India. . . . This [god], in Indian spiritual life, removes barriers and obstacles. And then if there’s a situation in which there is a negative energy or I’m not managing to communicate with a person very well . . . and I want to also improve that relationship and strengthen it. There’s a song that I believe is Hawaiian that is called “Ho’oponopono.” . . . It means, “I’m sorry. Forgive me. I love you,” and I sing this song, I listen to it, and it gives me a lot of peace because it is a song that you can sing to yourself.

**Traveling.** Traveling was another activity that helped participants build their inner strength. “I love traveling.” “I have been many places in the world and attended many social programmes.” “I love travel, and I find it the most exciting thing in life.”

Some participants described how traveling helped enhance their confidence. In discussing her trip to the WILD program, for example, Fatima shared,

It has improved my confidence, because I traveled alone from here in Malawi to the US, and I also managed when I was staying with a host family. . . . I was not assisted by anyone, and that has helped me to build my confidence.

Maru expressed a similar sentiment about traveling, “It helped me . . . to know the experience of traveling alone and really was just a good experience.”

Other participants described how traveling built their inner strength by fostering



their sense of connection with others. Balkissa explained,

I very much enjoy traveling, meeting friends and developing friendships in different countries. . . . Through the process of traveling, I have met some people . . . from all over the world with a variety of disabilities and a variety of stories . . . [which] has been inspirational for me to make a change.”

Gloria shared, “Travel widens my perspective. I enjoy visiting new places, meeting new people, learning about the different cultures and setup in each place.” Charity reflected, “It’s good to visit different countries, to meet other people, to get the experience.”

***Practicing self-care.*** Participants took action by engaging in different types of self-care. “I try to take care of myself.” “It’s important for you to take care of yourself.” Participants mentioned a variety of self-care practices including writing, enjoying physical activity, doing arts and crafts, and spending time with loved ones.

Some participants practiced self-care through creative writing and journaling. Maru and Mbalu wrote poetry that they shared over email and Facebook. In sharing one of her poems, Mbalu explained, “I said [to myself] . . . I should say something about the things that went wrong or that are wrong in the society and that nobody seems to care about. So based on that, I wrote a poem.” Maryana discussed the benefits of keeping a journal: “That [difficult experience] is empowering, because what I’m doing is I’m writing down how I feel about the situation, and I’m trying to take care of myself. . . . Yes, I feel much better when I write things down!” Balkissa described her practice of photo journaling. “What I keep close to me are these cherished experiences that I record through photographs and video to keep with me, to remind me of these great times.”

Participants also engaged in physical activity as self-care. Maryana said, “What keeps me going is sports, to tell you the truth. That’s a big one for me.” Gloria shared about her mind-body practice. “Every day, I try to do Yoga for half an hour in the

morning before I start my work. This helps me to stay fit and gives me the energy to focus.” When I visited Charity, she spoke about beginning to practice swimming at the Moban Hotel with her husband: “It is even important for us to have at least one day a week to go for swimming. . . . It is empowering . . . to do sports. Swimming is very important to our life.” Balkissa and Maryana mentioned dancing. Balkissa said, “I just love dancing. I would go dancing all the time.” Maryana delighted in dancing Flamenco with castanets: “I enjoy it very much. Oh yeah. I love it!”

Other forms of art and craft arose in participants’ descriptions of building inner strength. Hen and Melba both mentioned singing as part of their self-care. Lizzie spoke about doing woodwork with her husband. “I’m very hands-on, and the woodwork is perfect because my attention to detail is a bit scary [laughs]. So that is something I enjoy a lot.” Bárbara shared the types of films that motivated and fortified her:

I like social movies that approach disability—for example, *My Left Foot, I am Sam*. There’s a movie that I can’t remember the title of right now, but it’s about a man who runs with prosthetics in his legs. . . . Those are the kinds of movies that motivate me and that I like watching.

Gloria named additional self-care activities that helped her relax and connect with others:

I try to listen to music, [especially] old film songs, which really helps me to relax. At nights, I watch television for some time, and then when I go to bed, I read some books. I love to read all kinds of books (fact and fiction). If I am overstressed then I read fiction to relax. I also keep in touch with my friends through phones and mails. It’s always nice to stay connected with friends. If I get a weekend free, I meet my friends . . . [or] I take my parents to my sister’s house to spend time with them.

**Acting in pursuit of self-advocacy and social justice.** Participants manifested empowerment by actively pursuing self-advocacy and social justice. “Let’s use these talents and skills to help others also.” Their actions factored into their identity stories—“We are activists”—and arose all throughout their empowerment journeys as they raised

their awareness, navigated barriers, and drew upon supports. “After you’ve given me the information and you’ve empowered me, I want to go out there and act.” They drew upon their individual sovereignty and strength—“I can do it. Let me do it myself”—as well as on collaborative and collective power—“With the union of people, many things are obtained.” Mayette offered a simile for advocacy that combined participants’ general dedication both to individual sovereignty and to community:

For me, the [disability rights] law is like a food: it’s already on the platter. We will not wait to let somebody get the food on the platter and give it to us. We can now get the food [ourselves] and make it available to everybody, share it with everyone.

Specifically, participants discussed self-advocacy and social justice actions that included conducting research, sharing information and skills with Deaf and disability communities, raising public awareness, using the media, networking and navigating complex systems, insisting and resisting, serving as collaborative leaders, and empowering new leaders.

***Conducting research.*** Consistent with the major value that participants placed on education, they conducted research to inform their social action. “Wherever I go, or whichever organization I meet, I am enquiring about the differently abled community . . . [and about] any programs for them.” “Being a leader . . . I have to learn more from other people in order for my organization to be more equipped, enhanced.” Participants sought to learn from programs in other countries and communities, and they also conducted research within their own communities to learn what people most wanted and needed from programs and services.

Participants informed their activism work by researching the policies and programs for Deaf and disabled people in other communities and countries. For example,

Balkissa described traveling to eight countries in West Africa and to Australia: “To discuss how we could help the deaf organization in our regions . . . how to make our school better for the kids, and how to improve the curriculum and the program.”

Bárbara’s experiences at a training in Japan motivated her to begin advocating for better policies surrounding personal assistants in Peru. Charity’s attendance at international conferences in Kenya and Uganda inspired her and her colleagues to start the National Organization of Users and Survivors of Psychiatry in Rwanda. Lizzie researched the effects of aging across the world as well as the types of disability consultancies in Australia, the United Kingdom, and United States as she developed This-Ability Consulting. Mayette traveled to conferences across the Philippines and in Japan, South Korea, and Indonesia to inform her work at KAMPI, particularly to learn “The mechanisms that an ASEAN country has in involving all persons with disability to have their suffrage.” Rose-Ann went on a “study tour” of women’s health centers in Jamaica to research and design a sexual and reproductive health program for people with disabilities in Barbados: “And we came up with a whole host of information, ready to work.”

Participants also held focus groups and solicited feedback from Deaf and disabled people in their own communities. Mayette said, “You have to make a plan of action, but a plan of action doesn’t mean that all of the plans come from you as a leader. You have to also consolidate from your members what they want.” Charity explained, “[For] my research about the strategic plan of people with psychosocial disability . . . we had to get some of the ideas from them [the people themselves] to see what they need, what they really need to be done.” Maru shared the topic of her postgraduate thesis: “My postgraduate thesis was about labor inclusion for people with visual disabilities. . . . I did

some interviews.” In addition to embarking on study tours, Rose-Ann asked people in her community what they wanted from a sexual and reproductive health program: “We had a series of focus group meetings with the parents [of children with disabilities], with the disabled, with the Deaf, to get their input on how we go forward.” Fatima and Mbalu tried to learn why families were not sending their disabled children to school. Mbalu shared,

We used to go to schools as well and do outreaches. . . . Most of the stories they would tell you, “There is a girl who is disabled. She used to come to school, but now she’s not coming.” So we would take the address to go to the house to find out why.

Maru described an observational study that she conducted with two of her orientation and mobility students—children to whom she taught cane travel and other navigation skills.

It was like an analysis for me [for my own edification]. . . . There were two children, one who was in the mainstream education system, and the other was in special education, and I worked with them both. They were the same age, so they basically had to have the same knowledge. They were in the grade when they had to learn to read and write in braille. And at the end of the year, the one that was in special education [at the school where I teach] ended up reading and writing in braille. And the one in the mainstream school knew three letters because the teacher there didn’t know Braille. He just had the kid playing there.

When I next spoke with Maru to follow up on our interview, she reported that she had started tutoring children in braille out of her home to try to supplement the education that they were receiving at their inclusive/mainstream schools. Maru’s dedication to sharing her knowledge and skills with others mirrored a wide-ranging tendency among participants to educate the Deaf and disabled people in their communities.

***Sharing knowledge and skills with Deaf and disability communities.*** Providing education and training for other Deaf and disabled people was an enormous part of participants’ social justice work. They addressed the barriers they noticed in their

environments by disseminating information and by teaching important skills. Some participants specialized in working with children, while others focused on teaching adults.

Participants constantly strove to share information with Deaf and disability communities. “Oh my goodness, I have learned so much about empowerment and about how to bring information so that information can help people.” “I am very motivated and want to teach and disseminate information so that we can improve the lives of other people.” “That’s empowerment, taking [our] experiences . . . and passing them on.”

Participants told many stories about their specific efforts to share information. “When I became president [of an association of the Deaf], any information I got . . . I would pass it on to people so that everyone was in the loop and everything was transparent. . . . Information is so important for us.” “I’ve found that most of the women with disabilities do not give much attention to their health. . . . So whenever I get a chance, I used to include one session on health in . . . training programmes that I have conducted.” “It came to my mind that maybe, to us women with disabilities, it could help if I could discuss with my friends who have different disabilities how to prevent themselves from getting HIV and AIDS.” “My plan in my organization, it is to mobilize women with psychosocial disability to get more knowledge about their rights.” “I’m concentrating on educating people about disability rights, letting people know that they have rights, and those rights, you should not allow people to abuse them.” “I’m expecting and I’m hoping to get this information to [Deaf and disabled women] about their rights and domestic violence and all the health issues to just empower them.” “[I want to share] information about human rights, violence against women, and health-related

information—specifically pregnancy issues and how to encourage women to work together to overcome barriers.”

Some participants specialized in teaching Deaf and disabled youth. “I’m working with the youth—boys, girls, young mothers, parents of children with disability—I work with them. . . . I do teach those children.” “I do some education programs for children with disabilities, and step-by-step, I go forward to extend my organization and to extend the opportunities for people and children with disabilities.” “I continue to work with kids [with visual disabilities] doing what I like- helping them, training them.” “I’m doing my best to empower and give, to start with younger children and girls, to provide Deaf people with education so that they have more opportunities when they become adults.”

Participants also sought to impart practical and vocational skills to adults. “I’m a wise manager of money, and I can teach [other Deaf/disabled women] to be able to manage their money well.” Future employment was a primary end goal of skill building. “I trained many people . . . [in] computer skills, so they can use the computer to get a part-time job and also [in English because, if PWDs in my country] speak English or read English, they can also apply for jobs.” “I have organized aesthetic hairdressing training for 15 Deaf girls. When they got done with the training, some have found work in hair salons while others opened their own small businesses and make a good living.” “I trained some of the women with psychosocial disability about these handicrafts. . . . And when it comes to the trade fair, I just rent a place where they put those things [their wares] and they sell them for themselves.” “[I] set up a program . . . to provide training . . . so that [Deaf] women who develop independent living skills can work and be

employable in the textile industry. . . . We also teach them skills for how to work in a kitchen.”

In addition to improving employability, participants conducted skills-based training with personal empowerment as an end goal:

I went around to all-woman groups teaching [parenting skills]. . . . [A woman who] has a physical disability or who’s blind, she can learn how to use a different method of having a child, caring for the child. . . . That is empowerment because I am giving them skills to use.

***Raising public awareness.*** Another important aspect of participants’ self-advocacy and social justice actions involved raising the awareness of hearing and nondisabled people. “You cannot assume that all persons in the community know everything you know, because they are not part of your group. So you have to educate them, educate them.” Awareness campaigns focused on reducing the educational, access, and attitudinal barriers that faced Deaf and disability communities.

To address educational barriers, participants provided information to and conducted trainings for the parents of Deaf and disabled children. “I try to communicate with the parents of children with disability.” “My job . . . to talk to parents with children with disabilities to have confidence, to build confidence in their kids.” “I think we have to sensitize even the families of [children with disabilities] to take them to the schools.” Fatima described the effects of one of her outreach efforts:

We had an awareness campaign, trying to speak out to the community about the good side of sending their children with disability to school. . . . It was on Friday, and on Monday, a lot of parents of children with disability went into our school to register those children.

Participants also sought to diminish educational barriers by training teachers and volunteers to support the Deaf and disabled children who attended school. Maru shared,



“I work on inclusion projects, training teachers so that they know how to deal with kids with disabilities.” Nandar sought to address the serious dearth of professional sign language interpreters for Deaf students: “I organize a huge volunteer crew, and I train them in sign language to help the deaf people to attend regular school. . . . They are not professionals, but they only can help.”

A few participants targeted educational and attitudinal barriers by teaching nondisabled children how to be accepting and supportive of their disabled peers. Atika explained, “In the coming days, [youth] will understand and they will try to change our society and the place for disableds.” Nathalie shared, “We work also with young people to help them to understand that [disabled people] are capable and to just change their perspective.” In describing various educational accommodations, Nandar said simply, “Classmates can also help each other.”

Participants also sought to raise awareness about access to employment. In addition to her professional efforts to promote the employment of people with disabilities, Lizzie described receiving a personal job offer after educating a perspective employer. “I think I got the offer because I happened to mention to the lady who was looking for a manager that there is a disability law in Kenya and that organizations are required to reserve a certain percentage for disabled people.”

Mbalu spoke about raising awareness about environmental access.

So we’re having a lot of workshops in different areas. . . . Even the community halls that we were using [to conduct the workshops], they were not handicap friendly. So at least we are able to sensitize them that, whenever a project comes for a community, you should have it in mind that when you’re putting up that social—whether it’s a school or community center, a hospital or a hall—you should make it accessible. There should be a ramp for people using wheelchairs.

Rose-Ann also described raising awareness around environmental access as part

of the Fully Accessible Barbados (FAB) program.

We've developed criteria. . . . We ask, for instance, "Do you have an elevator? Is your elevator wide enough for wheel chairs to get through? Does this elevator have braille for the blind? When I come into your car park, do you have a space for me to park? Is there a space wide enough for a wheelchair to be able to get out safely without another car coming to knock the wheelchair?" So all of those things we look for. And if by chance you don't have them, we make our recommendations.

Participants raised awareness by working with governments and NGOs to improve education and access on a policy level. "Because of my role as project officer, they come to me looking for ways to really educate the public . . . and help guide the government." "Now I am a trainer of CRPD in my country." "I explained to them, 'Most of the UNICEF processes are very good, but not good for children with disability. . . . A disabled child is also a child.' . . . So I gave awareness to them." "Save the Children is also doing education for children with disability because we advocated to them. At first, they didn't know about children with disabilities. They only focused on non-disabled children attending school."

In seeking to decrease attitudinal barriers, participants sought to change the public's perceptions and expectations of Deaf and disabled people by addressing specific groups within their communities. Among other groups, participants worked with the police, medical personnel, and other NGOs that did not specialize in disability concerns. Lizzie shared, "My work is to get more non-disability organizations involved in disability." Mbalu spoke about her work with the police and with nurses:

In my country, we have certain areas that have high numbers of disabled people living in them. Because after the war, camps were built in certain areas, like the Grafton community, the Allentown community. . . . So we are having a lot of workshops in those areas, sensitizing the head of the communities, the police, the nurses, the teachers, yes all of them. . . . Yes. And we are able to talk it out. Then later, we do follow up. . . . And you know, at the end of the program, the

assessments are like, “Everybody, we are happy. I think we are able to know how people [with disabilities] do feel.” . . . They became aware.

As part of her job, Nathalie described working with a range of NGOs to help them shift from a charity ethic to an empowerment approach that included Deaf and disabled people in their services.

So we work with organizations, for instance, like a religious organization that may have a different view, that may look at the handicapped with pity perhaps. We really work to combat that mentality, to break that idea because they’re coming from a perspective where the handicapped ought to wait for pity or charity contribution or something like that. We have a campaign for those people [who work in the NGOs] to learn to help the handicapped by encouraging them to be autonomous and not be dependent.

Participants also held community-wide events to raise awareness and to help change attitudes and expectations. Mayette described some such events.

In the Philippines, every last Monday of March declares as the Women with Disability Day. . . . Then every third week of July, we celebrate the national DPR—national disability prevention and rehabilitation—week. It’s around all over the Philippines. Last July, I had very, very successful activities. For its opening, we had a mass and a motorcade for the awareness, then we had an opening program where all offices were invited, government officials were invited. Then we had a general assembly for all the leaders in the entire region. Then on the second week, we had a training on the early detection and prevention of disability. Then after that, the sign language training for the front liners [to interpret for Deaf students] who got admission in schools [colleges and universities].

Sometimes, participants raised awareness and combatted attitudinal barriers by using themselves as examples. In keeping with this philosophy, Fatima made sure to be conspicuously present around her Blantyre community. “When [ever] there is a function that a person wants to take part in, I’m there.” Rose-Ann similarly described her comportment in Christ Church:

I almost have to advocate here proving that when [people] see a person with a disability, they say “Hey, that’s just a normal woman doing her shopping,” and they see me in the restaurants, “Hey that woman has a fun dinner. I have to eat.

She has to eat.” . . . I think I am placed strategically here right now. I’m doing what I have to do to bring that awareness for persons with disabilities.

Mayette described personal visibility as an important step in being a leader.

First, you have to be visible. . . . You have to sit in their offices [the offices of government officials] every now and then and have to go, “Hi, good morning, hi. Yes, what updates can I get for you?” . . . [And] tell them . . . your plan, what you want to do.

Other participants recognized the value of visibility and turned to the media to further their activism work.

*Using the media.* Some participants had a particular knack for using the media to raise awareness, change cultural attitudes, and mobilize action within their communities. Bárbara, for example, presented on the radio and on television as a regular, core component of her activism work. Fatima shared, “I’ve been on TV. I’ve been to radios several times.” Nathalie mentioned, “I was twice the host of two broadcast programs on the rights of disabled women and the employability of people with disabilities.” Lizzie identified being interviewed as an empowerment experience: “I did an interview with Management Sciences for Health, the leadership Management Group project. I got a lot of airplay for that interview, so that was very empowering. It was on their website, on Facebook.” Mayette spoke about her work with the media as a tool for empowering others: “Tri-media . . . always call me for an interview, especially when it shows on the television and radios. It really serves as advocacy, informing the society on what the persons with disability have contributed for the improvement of the environment.”

Participants used a variety of media—including radio, television/video, and theater—to raise awareness about particular projects and programs and to help change cultural attitudes. When Rose-Ann helped to launch FAB, it was a media event: “We did

video footage. It was a big thing when we first launched it and awarded the first recipients, because our prime minister actually was the honored guest, and he presented the awards to those first recipients. Mbalu designed a “Hand in Hand” project to raise awareness through the media: “I want to have a radio program at least twice a week . . . where we could be doing sensitization. . . . How can we work with people with authority in including us in community development?” Nathalie described using film, radio, and theater to change the public’s attitudes and expectations.

We have documentaries, films that we provide, that are seen on TV that give the general population information and show that people with handicaps can succeed with education. By radio, we have people come and testify and tell about their experiences and how successful they have been. We have demonstrations of wheelchair basketball and bicycle riding, so people can see the talents that the handicapped have. We have theater, a theater forum for the public, and so that helps people change their mind about the handicapped through theater.

When Nandar decided to raise awareness and change attitudes around ableist language in her country, she did so during a television interview.

It was [on] a worldwide TV channel, and the name is Democratic Voice of Burma (DVB). . . . One of my girlfriends and I accepted an interview with them for the first time. At the time, they also used that [Burmese] terminology, “not able and not strong,” and also they asked me a lot of [personal] questions. . . . I didn’t answer those questions, and I made a little twist on their approach. . . . “These questions have negative impact for people with disability, and these questions make some empathy or sympathy for people with disability. We don’t want that type of feeling, we want to be the spiritual empowerment and we want to be included and acknowledged.” . . . And at the end, I also changed how to call their terminology. . . . I changed it to [a Burmese term that] means the same meaning as differently abled. . . .

Participants also used the media to mobilize action in their communities. Nandar’s interview to the DVB, for example, prompted action on the part of the television channel. “After that [the interview], they changed a lot, and now they give a free channel for the online video for the disability issue.”

Fatima used the media to help mobilize a public call for action after the abduction of V, her student from the learning center. Fatima had felt frustrated and heartbroken because V's parents had chosen to accept a bribe—money they needed to buy food—in exchange for dropping the charges against the man who had abducted their daughter, so Fatima turned to a journalist who helped her to raise a public outcry.

I went into the television. I met this guy, he's a famous guy, knows how to do his work in Malawi. I went straight to him. I said, "I want you; I want to take you into [V]'s parents. This is what has happened." And I went together with that man, that reporter. That reporter started asking [V]'s mother about the issue. . . . So they were recording her, and that news came into the television of Malawi. . . . So it was around seven o'clock in the morning when that scene was being on our television. And a lot of people took part. They came. They started calling me and started stressing the man who paid the money [to the parents]. And we found that man who raped the girl [V]. As I'm talking, the man is in police custody, just because I used television, you see?

*Networking and navigating systems.* Participants' abilities to make professional connections and to move among and within multiple systems appeared to be integral to their self-advocacy and social activism. "I have contacts, and I know important people." I just keep on asking them for what I want. . . . I just keep talking to them. . . . If they are not responding, I ask for other people [up the hierarchy]." "We have to be here in one group and share the ideas." "I used my identity as a person with disability and an empowered woman to make linkages for the welfare of my fellow persons with disability."

We as persons with disabilities need to seize every opportunity there is to get involved, not only with the likes of ourselves, but get involved with other programs outside that may not be related to disabilities. . . . I guess they call it networking.

Participants placed a strong value on networking and building professional relationships. Mayette explained, "Networking with some civil society organizations, it's

easy for me. . . . And also, having networking with my local government unit is easy for me. . . . If I have my skills in networking . . . I know that's a benefit for my organization." After encountering patronizing congressmen who would not listen to her, Melba decided "to make allies with women in congress." Balkissa shared, "I'm involved with the board of an organization of seven western African countries. It's related to the World Federation of the Deaf. . . . While I was traveling around these different countries, I would talk to people and network." Nandar indicated that networking was an important aspect of the community development and civic empowerment training she attended at Chiang Mai University.

I got a lot of knowledge and experience and networked with [other participants]. Some are working for the international NGOs. Some are working for the youth. Some are working for the women. Some are working for the government, and some are working for the disasters. So . . . I [now] have a network with them.

In their identity and empowerment stories, participants described how they learned to navigate hierarchies and systems as part of advocating for themselves. For example, Balkissa navigated school and governmental hierarchies as she sought to pursue her education beyond the sixth grade, and Hen engaged in a similar process as she advocated to use braille materials and a sighted scribe for her high school certificate exams. Atika shared how she advocated for environmental access at her place of employment: "Even once I asked the high commissioner of Britain at the embassy over there . . . because I was the first disabled to come in the whole [organization]. . . . Then they made a new accessible washroom; they made me ramps." As she shared her story about the inaccessibility of the national teacher's exam, which she was required to take through the Ministry of Education, Maru described how she had to wind her way through various systems to advocate for testing accommodations.

So I began some [advocacy] in order to say that they could not order me from my job because they did not adapt the test for me. . . . I did not have equal opportunities. So I had to go to a defensive organization in the city and file a lawsuit. I spoke with the department of labor. I had to speak with many departments to have my rights met so that I was not sent from my work. . . . It's been a long process, with one department and another department. I had to go to Quito to continue the fight. . . . After I went to trial, they called me to take the exam, and I was able to take someone to read the questions for me. I passed the exam. . . . If I had not done anything . . . then they would have taken me out of my job.

Participants drew upon their professional networking skills and self-advocacy experiences as they navigated hierarchies and systems in their social justice work. "We are doing an advocacy. We are thinking how we can work together with the government, how we can work together with different institutions." "I'm advocating with our government, our community to have access for all." "So I try to be a joiner. . . . I can give information to disabled people and also to the government organizations, and they can work together." "I became more empowered in the sense that I gained more fighting spirit to face local officials to advocate for PWD [persons with disability] laws in my area. . . . I kept on advocating and making linkages with other agencies."

Nandar related a recent experience in which she advocated for appropriate accommodations for a student with cerebral palsy.

Yes, I want to tell her story as a success story. . . . At the time, she was trying to take the entrance exam for the university. That's so important in our country. . . . I'm a computer engineer, so I showed [her]: "Here's a good chemistry software and mathematical software," and taught [her] how to use this software to type and to talk [dictate] something. At the same time, I needed to approach the headmaster of her school . . . to get the permission to use the computer during her exam. . . . The headmaster said that they needed official confirmation from the Ministry of Education because . . . our country is very centralized—all the education exam decisions are at the Ministry of Education. So I [next] tried to approach the Minister to get the official permission. . . . When I presented [the student's] problem and condition, they didn't know how to do for her and thought it was impossible for her to take the exam. I said to them, "No, no, no, it is possible. I have the solution . . . and so can I assist you to get the solution?" They happily



worked with me . . . and they discussed with me how to get supports for her. . . . And this is the first case in Myanmar taking care of everything. . . . She sat the exam. They brought the computer and gave the supports for her, and now she passed it.

Charity continued the story about a genocide survivor with psychosocial disabilities who experienced police violence and physical restraint, sharing how she and her organization navigated the legal system to redress this injustice.

What I did was to go immediately to the police, and [insist] that the police who did that were to be arrested. After arresting, this is where I intervened and brought someone from the court . . . to follow the high court's measures. . . . So we brought a lawyer. From that, we made some of the press release to the media, where they announced everything that was happening to that person [survivor]. . . . From there, I intervened with this worldwide network. They told me that they have to bring two lawyers, international lawyers to come and follow that crime. . . . This will be the next step, for the international lawyer to come intervene.

***Insisting and resisting.*** Participants' self-advocacy and social justice work involved times when they needed to take a steadfast position or to express resistance. "I'm a person who likes to fight a lot [for social justice]." "It's our role to fight for our rights." "Disabled warriors, we're fighting for our rights." "Disabled women can fight for our right to open-up the way for the world to see / know what we can do." "It's about being strong and standing your ground." "To some [people], you have to be really aggressive and put your foot down and say, 'No, this is what I am. You have to accept me as I am.'" Their willingness to promote their perspectives or push back against dysfunctional or unjust systems complemented and combined with their efforts to raise awareness and to network and navigate hierarchies.

Expressing truth to power was a significant form of participants' insistent self-advocacy and social activism. Sona asserted, "I'm blunt. I'm direct. . . . I just say it as it is." Fatima said, "I have a voice to make." Mayette declared, "Everybody can describe

me as a woman with big voice who has no fear. I always speak in front of people, as long as it is for the welfare of my fellow persons with disability.” Mbalu stated, “I’m fearless. So I can meet with anybody as long as I’m saying the truth.” Nathalie, who described herself as generally shy and quiet, described possessing a similar courage. “I’m not afraid to go to organizations, to politicians, to become involved in forums or organizations and to be a voice for the handicapped and to be outspoken when I need to be.” Rose-Ann explained:

I try to practice this constructive criticism, because I’ve come to the reality that you are just as guilty as the other person if you say nothing. If you’re innocent, and you see that there is something wrong, if you shut your mouth, you’re just as guilty as all the rest of them, not saying anything. You have to say to yourself, “If you are to improve the situation, you need to speak out.”

In their identity stories, participants recounted times when they stated truth to power in order to advocate for themselves and their perspectives. In their pursuit of education, Maru advocated for increasing the light in her family home, where she was home schooled, and Mbalu made a forceful case to her family for returning to school after her spinal cord injury. Gloria promoted her individual sovereignty by informing her parents that she was happy being single and that she wanted them to drop their pursuit of arranging a marriage for her. Hen opposed her family’s restrictions on her mobility by stressing her deep, life-affirming need to work outside the home. Fatima resisted sexism and abuse by speaking frankly to friends, family, and potential suitors about her decision not to take a lover. Maryana said “Nope, no more” to a hearing colleague whose behaviors patronized and tokenized her. Last but not least, as a mother of a multiply disabled son, Mayette defended the inherent worth of her child to family, doctors, and a courtroom full of people.

During the period of time when Melba was being harassed by her former boss, she advocated for herself by expressing her truth with clarity and strength.

When my boss threatened me, I told him, “Everything you’re saying to me, you don’t have to tell me on the phone, you need to tell me face to face and with someone else present.” . . . I don’t know where I found the strength to say that. . . . So then on Tuesday, there was a meeting, and everyone was there . . . and he said, “I don’t know why you say that I have harassed or attacked you in any way. You lie when you say that I have shown aggression.” So I gave him a list of all the things he had forbidden me to do: he took away my computer; I couldn’t leave the building; I couldn’t give speeches; I couldn’t have meetings with other associations. . . . I said, “Doctor [referring to my boss], if you allow me to be here, then allow me an opinion.” Then I said, “If someone takes away my computer, and my computer is the instrument with which I work, then that person is harassing me.” And then there was silence. Then he said, “Well, we’re going to end this meeting, but all of these things are lies.” And then I said, “I have proof of what I’m saying.” And then he turned around to the person who was transcribing the conversation. He said, “You take this out, take this out, take this out.” A few days later, they told me, “We’re going to send you the minutes of the meeting for your signature.” And I said, “If I agree with what it says, then I will sign it. If not, I won’t sign.” They never sent it. But it was all resolved in the end, thanks to help from the heavens.

Participants also described stating truth to power as part of their activism work. Mbalu, for example, vociferously spoke her truth when, on a school outreach program, she encountered a six-year-old disabled girl whose mother was “beating the girl up all the time,” and she encouraged the girl to speak out as well.

I told [the mother] that the [next] day she will raise her hand against that girl, I’ll take her to the police station and I’ll take her to the human rights commission. . . . And I told her, I said, “I’m a disabled woman, but I’m a graduate. I have abled people that are working in my organization. So this girl [your daughter] can become somebody with a future.” . . . And what I did, I started inviting [the mother] to my workshops, and everything changed. The teachers are now saying the girl is doing very well. At first she was so scared, scared of everything. She was so nervous, but now she is so relaxed. And do you know what I did? I told the girl that, “If anybody raises his or her finger against you, let me know. Nobody has the right. You be in school. Nobody has the right to beat you up.”

In her work, when Gloria encountered women leaders who were overshadowed by their man-identified family members, she made a point to speak out both to the women and to the men who were trying to usurp the lead:

What I would do is just say [to the men], “Okay she’s the one, she’s the leader.” [And then I would say to the women,] “Can you please come in the front?” I would ask her to come to the front and say, “I want to hear you. I want you to speak out. I don’t want your husband or your brother or somebody to speak out. You are the leader. So you voice out. You have to take decisions. You have to tell me what the issue is and then how you handle this.”

Occasionally, participants also chose to take action outside of official channels to resist an injustice. For example, in the face of national definitions of DPOs and of expectations about how to register her organization, Lizzie chose to reject the charity ethic of disability by developing This-Ability Consulting as a for-profit business.

Mbalu told a self-advocacy story about staging a one-woman protest on the way to her college graduation ceremony. She had been looking forward to receiving her diploma and to shaking the hand of the President. “So I was like, wow, everyone will see me with the president. They’ll know that there’s a strong woman here.” Even though she and her family left very early, they had trouble driving through to the university.

There’s a particular junction . . . all vehicles go to that junction before they go to the university. And I was stopped by some policemen. They said I should have a pass to go to the university. I said, “Well . . . I don’t have this pass, and I’m a disabled student, look at my wheelchair. This is my gown. I’m going for this graduation.” They said, no, I could not go. . . . Then something just came in mind that these people, they will delay here, and I will not be able to go there because of this complication.

To protest, Mbalu and her brother decided to turn their car perpendicular to the road to create a traffic jam.

So as soon as [my brother] did that, I took off the key. . . . I said, “I’m not going to move my vehicle until you allow me to go up [to the university].” And the other

[police officer] is like, “The president is coming.” I said, “Let him come. . . . I want to see how the president will get up there.”

Mbalu’s resistant action drew the support of her community, and the people in the surrounding cars put additional pressure on the police, both by witnessing the scene and by speaking out with Mbalu.

Everybody was like, “But you should know this girl! All of us know her! Why do you want to stop her?” . . . When [the police] saw the embarrassment, one of them said, “Well, you can go. Just go, go, go, and clear the way” [Mbalu laughs while clapping her hands.].

Sona described moving outside official channels to resist the targeting and trafficking of Deaf women from her community. When four women whom she knew were abducted, Sona took action.

There were four women that I knew of that just disappeared. . . . Their parents were certainly very concerned, and they let me know that their daughters had disappeared. . . . At the time when . . . all this happened, I was trying to find transportation and was able to procure a vehicle. It was a really old, old vehicle. . . . I have two men friends who are Deaf, and the three of us, we all drove up to Ghana and looked around . . . and we had to have our own money to go there and pay for gas. . . . So we were able to find the four girls. . . . We worked to explain to them [the young women] that their parents were very upset and concerned for them, and they should come home, but the people who they were staying with in Ghana were trying to keep them there and not letting them go. And then we threatened them with the police, “If you don’t let them leave because of the situation, then we will tell the police,” and that’s when they decided to make a change, allow them to be released. And we brought them back home to Côte d’Ivoire. . . . Oh my gosh, and then we got home, and the parents saw them, and they were overjoyed that [their daughters] were back and away from danger.

***Engaging in collaborative leadership.*** Whether or not they identified as leaders, participants all demonstrated community leadership in some form as they pursued social justice. “If you’re a leader, you have to act as a leader.” “It is good to become a leader because you learn more information about what happens, especially with us people with disabilities, [and] because you are the strength of all the women in your country.” “If I

leave them, who will be their leader?” “Sometimes peers, they appoint me, so I want to lead the people, and sometimes, it is not my desire, my responsibility.” “As leaders, we have to be strong and to do anything which we think is impossible, to make it possible.”

Organizing projects and programs comprised a large part of participants’ leadership responsibilities and social justice work. “I experienced my empowerment by my ability to organize my first project workshop.” “I have experience of organizing a lot of meetings, trainings, workshops. I know how difficult it is to get things done without any flaw.” “I started mobilizing people, thinking about how to write a constitution, how to write an organization profile. Where can I find the people who can work with me?” “It’s a lot. I basically coordinate all of this, you know, keep it glued together. So that is where the empowerment comes from.” The wide range of projects and programs that participants organized included advocating for women’s and disability rights; increasing the accessibility of physical environments, public transportation, and education; promoting the employment of Deaf and disabled people; improving health care; advancing adaptive sports; preventing domestic violence and HIV-AIDS; and raising awareness and reducing stigma.

Due to the pervasiveness of financial barriers, participants dedicated much of their leadership energies to fundraising for their activism work. “Where can I find some resources?” “I need to get funding to do something.” “I have to find ways to make us independent and sustainable.” “I’m happy that now I have managed to create a relationship with a funder.” Participants raised funds in a wide variety of ways. They wrote grant proposals: “Before we finish that program, we need to write a proposal.” They solicited funds in the community: “We went business by business, door by door,”

and they organized “small income-generating projects, such as the sale of cooking wood and coal, sale of vegetables and fruits, sales campaigns, sales of ice water, cream, and juice fruity, etc.” Although many participants mentioned their efforts toward fundraising, Mayette directly connected her ability to secure funding for various projects to her networking skills, to her identity, and to her sense of empowerment:

Being an empowered woman already, I have got a 3 million pesos project, which is the rehabilitation center for children and young adults with disability—1.5 million pesos for its equipment, 2 million pesos for the independent living rooms for the children with disability, 500 thousand pesos for the bakeshop. These are all funds coming from the national government agencies. Here, I used my identity as a person with disability and an empowered woman to make linkages for the welfare of my fellow persons with disability.

Throughout their social justice work, participants engaged in leadership by working to represent Deaf and disabled people. They formally represented others by holding myriad leadership positions as part of nongovernmental, governmental, educational, and telecommunications organizations. Their official leadership positions factored prominently into many of their salient identities. Participants also found themselves informally representing their communities by being the only Deaf or disabled women in their professional and personal environments. “I’ve found that, when I go to these conferences . . . even sometimes at the international forum, I’m the only disabled woman there. So the emphasis is on me to get the word out.” “I was the first person with a disability to attend that training. So at the training, all the participants were non-disabled people.” “Everywhere I go: I go shopping, I’m the only one with a disability; I go to church, I’m the only one; the university I went to, I was the only one.”

Just as they benefitted from the support of role models in their own lives, participants demonstrated leadership by striving to act as role models to others. “Being a

leader, you serve also as a model.” “I think I am becoming or I am a role model to my colleagues and others around me.” “I would like to do my work for the disabled community. I need to become a role model for them. . . . So I try to become a good leader especially for women with disability.”

Yes, I believe in example more so than words, because whenever I give speeches to poor communities, they tell me, ‘It doesn’t matter what you say. The fact that you are here talking to us proves that our [Deaf/disabled] kids can make it too.

Promoting and participating in teamwork was a significant way in which participants demonstrated their leadership. “When there’s a real leader, people follow him and they work as a team because that person knows how to get to people, how to motivate them.” “I strongly believe in the need for dialogue and compromise when trying to reach a specific objective.” “Yes, we are able to talk it out.” In her interview, Rojanet shared her belief that leaders should not tell people what to do but should, instead, value the ideas from all of their team members and foster a friendly working environment. Indeed, Rojanet received feedback from her colleagues that she is a good team leader. Gloria discussed the value she placed on collaboration by saying, ““I like to be in a team. . . . Being in a team really teaches us more as we learn from others.” Atika connected leadership and collaboration by saying, “At least I can start something good, and somebody else can help.” Nandar spoke about her organization’s cross-disability collaboration: “We collaborate with five different disabled organizations: two are physically disabled organizations, one is blind, one is deaf, one is learning difficulties,” as well as her recent work with organizations that do not have a disability focus, “I started to contact non-disability organizations, local and international together.” Mayette



extolled the benefits of being a collaborative leader by citing “The exchange of ideas” and by offering an active metaphor:

In group work, or in the office, I can say, I am a good team player because I will not play on by myself. . . . If I’m not sure that I can put the ball in the basket directly, I have to pass it to my teammate. Yes pass it to another one and [another] until the last person can put it directly [into the basket].

As an extension of collaborating, participants put leadership energies into building community. “I’ll be happy to see people being friends.” Sona, for example, described organizing “a three day event” in her community that involved “a presentation about domestic violence . . . a fashion show . . . [and] a soccer tournament just for women.” Balkissa explained some of the impetus for community building at the Association of the Deaf:

We see these opportunities for hearing women out in the country, and there’s nothing that is really entertaining that Deaf people can get involved with, so we set up different social activities for the Deaf community to get together. We provide loud music for dancing and just a different social environment for our community.

Participants also described harnessing community support during difficult times. Sona gave an example: “Any time a child is born, we set up a donation drive to give necessary supplies to mom and the girls: food, milk, clothes, diapers.” Charity organized a community support network in each district to offer peer support to women with psychosocial disabilities in times of crisis:

In the groups I formed, we selected three women in each group, where if a woman who has children gets sick and she’s taken to the hospital, the three who are elected are supposed to be back with the children, to care for those children who are behind. . . . [Having community] helps with transportation. It helps someone to go to hospital. It helps [to have people who can] go and get them food over there. It helps in different ways, in a small quantity, but it helps.

*Empowering others.* Participants' collaborative leadership intersected with their efforts to share knowledge and skills with Deaf and disability communities as they sought to train/empower future leaders. "What I want to do is just provide that support and empowerment so that they know that they can do it and that they can overcome." For example, Atika declared, "I'm working on women's empowerment. . . . We have to invest a lot of time for empowering women," and Mbalu explained, "That's the work I'm doing now, especially for women in my country, disabled people in my country . . . They're not empowered. Most of them are not educated . . . and we need to empower them." Mayette stated,

One of my goals [is] to make women with disability and also men with disability to be more empowered. . . . What we have to do now . . . is to go to the grassroots, organize [the people], strengthen them, and let their leader come out.

Nathalie outlined a similar aspiration: "The goal that I have is to encourage or empower other women to also become leaders for handicapped people and to make advocacy in other organizations in my country," and Nandar said simply, "My target is to empower people with disability."

Fatima defined empowerment according to this process of "lifting up" others.

Empowerment is to [support] someone to do new things, like me, I should say. Empowering is lifting up someone from where they are to be on top, like someone who is not educated, so that person can be now well educated—empowering him or her through encouragement—or someone who's not a leader, and through some encouragement, some training, some other things, can now be a leader.

Many participants described their specific endeavors to promote leadership in others. Nisha stated, "I always try to get other women to come out . . . and participate in the activism." Mayette explained how, after she benefited from many travel opportunities, she began to pass along those opportunities to others:

There were so many invitations I received from the national level regarding women with disability activities, but I sent my members to represent me, because I believe empowering other members in the group will be more strengthening, as it will enhance knowledge and skills.

Nandar described her work with disabled youth: “We go round and round again, and we train people with disabilities to become youth leaders in their communities.” Maru reported, “The workshop that I organized went well. . . . It was a workshop for about fifty people here in Cuenca where I had to train about leadership and rights for people with disabilities.” “Rose-Ann described a “breakfast club” that she organized for women with disabilities: “We had [modules on] self- empowerment . . . [sexual and] reproductive health issues, how exercise can benefit you both physically and emotionally, and [how to] be an advocate.” Melba discussed a series of workshops that she designed:

I designed an empowerment project. . . to put together empowerment workshops in each of the thirty one states in Mexico and then one more in the capital so that people with disabilities get to know their human rights, . . . increase their self-esteem and their self-confidence, and obtain tools to be agents of change in their own communities.

Gloria and Charity both made a point to mention how leadership training was an important manifestation of empowerment for everyone involved, including trainers and trainees. Gloria explained,

I can motivate other people to become new leaders. I know how nice I felt when I was a leader and how powerful I felt, so others also would really be looking for that opportunity, or they would really want to be leaders. And they can do a lot more being leaders, as I have done. So I started training people, empowering them in whatever manner I could.

Charity reflected,

When you go and train women with disabilities about leadership, that is empowering [an empowering experience for the trainer]. You are [also] empowering them to get to know their skills so that they can understand how they’re going to help their women right from the grassroots, up to the national level. That is empowerment also.

Overall, participants expressed a desire, not only to experience personal empowerment, but to share their power with others. They engaged in power sharing by accepting support from others and by giving support. “What is more important is giving to others what we receive.”

When I ask for support or help to do something for the disabled women in and around my community and I get the support or help, I am empowered. Also, if I call the disabled women to come together to discuss, to fight ahead for our rights and a better life, and if they respond, it also gives some empowerment.

### **Reflecting on Manifestations of Empowerment**

In summary, participants described experiencing and manifesting many aspects of empowerment. “Empowerment, it means a lot.” In addition to manifesting empowerment in their salient identities (Chapter IV), and in their awareness of self and of their ecological contexts (Chapter V), participants manifested empowerment through their personal approaches and strategies, by developing their individual and collective power-within, and by exercising their individual and collective power to act.

Participants’ personal approaches to pursuing empowerment both guided their empowerment journeys and served as manifestations of empowerment in and of themselves. Orienting to their values, for example, was an approach that strengthened participants internally and directed their personal and professional actions. In addition to orienting to education, awareness, and skill building (Chapter V), many participants discussed their faith in God, their family roles and relationships, and social justice as values that contributed to their salient identities, guided their pursuit of empowerment, and offered them strength and purpose. Working hard—planning and preparing, expending extra effort, and identifying as hard workers—was another strategy that

participants used to pursue empowerment. To counterbalance their hard work, participants also adapted to, accepted, and embraced the challenges they encountered in life.

In their accounts of empowerment experiences, participants shared three major manifestations of their power-within. Confidence—arising both from an inner reserve within participants and from the presence of family and community support—was one significant manifestation of participants’ inner power. Participants also manifested empowerment through their individual abilities and social freedom to make decisions. Their sense of connectedness with family, friends, and community (power-with) was a third source and sign of participants’ power-within.

Participants manifested empowerment by taking action to build and sustain their inner sense of peace and strength. They practiced their spirituality, in part, by attending religious services and dedicating time to meditation and prayer. They traveled outside of their communities to raise their self-confidence and to foster a sense of interconnectedness. In general, they exercised a miscellany of self-care activities, including creative writing, journaling, sports, dance, arts and crafts, and connecting with others.

Participants also manifested empowerment by actively pursuing self-advocacy and social justice. Consistent with their orientation to awareness and their personal pursuits of education, participants conducted research both in and outside of their communities to inform their activism work. In turn, they provided education and training for other Deaf and disabled people and strove to raise awareness, change cultural attitudes, and mobilize action within their broader communities. They held workshops

and community-wide events, gave interviews, and shared stories through a range of media to effect change. Sometimes, participants advocated within formal systems, making professional connections and navigating official hierarchies, and other times, they worked outside of or against these systems, expressing truth to power and protesting systemic injustice. All throughout their self-advocacy and social justice actions, participants demonstrated collaborative leadership by organizing important projects and programs, fund-raising, representing deaf and disability communities, serving as role models, promoting teamwork, and building community. Last but not least, they sought to share power with other Deaf and disabled women and to support them in taking on leadership responsibilities.

**Empowering contexts.** Because power within various contexts was a theme that arose throughout participants' accounts, it is a topic worth a final mention. Participants recognized that empowerment, in addition to manifesting in their internal strength and individual and collective actions, must also transpire within greater social structures and institutions. As they reflected on the terrain of the empowerment journey, for example, they articulated the importance of receiving an education: "If disabled women get the right to education, we will be empowered with many things." They specifically emphasized the necessity of socioeconomic empowerment: "I am in agreement with the empowerment of disabled people. To be considered in life, you have to be self-sufficient economically." They stressed the importance of living in an empowering family and empowering society: "I would like to say [something] about empowerment, not only family empowerment, but also [within] society. We need more assistance; we need more barrier-free conditions. . . . If society wants to include the people with disability, then we

can [be] included.” “Yeah, inclusion is also another type of empowerment.” In short, individual and group empowerment is not enough, if Deaf and disabled women do not live in empowering environments.

**Some final thoughts on identity and empowerment.** Participants expressed the belief that their intersecting salient identities and the multiple layers of their empowerment experiences connected with one another (refer to Appendix J). This phenomenon was apparent in the overlap of their identity stories, their empowerment journeys, and the manifestations of empowerment in their life experiences. “Yes, there is a connection between my identity, my experiences of marginalization, and my empowerment.” They articulated the connection of identity and empowerment on an individual level: “Our empowerment interacts with our identity in that personal empowerment is becoming more aware of one’s self as a unique individual.” They also acknowledged that identity and empowerment transpire and weave together within a rich and intricate context:

I think that my empowerment experience connects to my identity as a [names intersecting, salient identities] because, as a human, one needs empowerment to move on swiftly in all aspects of life—i.e., socially, physically, religiously, culturally, etc. And I think that my empowerment experience is not out of place [context] but connects to my identity.

Fatima described the collective empowerment that can arise from bringing together people with different identities, backgrounds, and experiences.

Different identities also encourage empowering, because we learn from different cultures, we learn from different ideas. I came from Malawi and Lizzie is from Kenya. I can tell you what I do here in Malawi, and Lizzie can also tell me what she does in Kenya, and that’s part of empowering. The other thing which I was not doing here in Malawi, because I listened to Lizzie, I can start doing it here in Malawi. Just because Lizzie listened to me, the other thing which she was not doing in Kenya, she can now start doing it. . . . Yeah, sharing identities. Here we are, women with disability.

**The importance of stories.** Over the course of this project, participants lauded the importance of stories in bringing about social change, and they expressed a sense of gladness around the opportunity to share their stories, particularly with people living in the United States. Consequently, these results chapters conclude with some of their words—words that speak to their opportunities to share their stories.

I just wanted to extend my appreciation. I'm really happy you took this time . . . showing an interest to get to know us, and I think it's nice to be able to share our stories. So thank you for taking the interest. (Balkissa)

“Thank you so much for giving me time to share about my views and my life” (Gloria).

“I have an open heart now. All of the things I shared with you, I'm happy” (Hen). “Oh, thank you! Now I feel so happy. I feel like we've connected” (Maryana). “I'm very proud, I'm happy to be interviewed, and I hope many people will read my story. And they can see how women with disability in the Philippines work” (Mayette).

All the information I have given you is just and sincere. . . . I think my experience and my story can be a testimony to help and change positively the image of women with disabilities. . . . As natives to the USA, it is not always evident that you have knowledge about the socioeconomic, political, and cultural life of the disabled woman from a poor country such as Burkina Faso. My experiences of empowerment are proof that your country, the US, plays a key role in the integration and empowerment of the world's disabled women especially those in developing countries. . . . To me, it is fundamental and very sensible that you have this information. . . . Thank you very much for allowing me to lovingly share my story with you. Make good use of it and God bless you! (Nathalie)



## CHAPTER VII

### DISCUSSION

Over the course of this study, participants shared their intersecting salient identities and multilayered experiences of empowerment in the stories of their lives. Their stories referenced the journeys that they traveled in developing their identities, increasing their awareness of themselves and their environments, and growing their individual and collective power and strength. Perhaps growing would be another apt metaphor to use in addition to journeying. Growing can signify both a developmental process and an intentional act of cultivating life. Like De Clerck's (2016) concept of Deaf flourishing, growing could refer to the process of coming to experience "good and dignified lives" and include "constructs of identity, empowerment, development, and well-being" (p. 20). While journeys tend to follow the linearity of time, growing, both as a process of becoming and as a conscious act, brings to mind the many different plants, wanted and unwanted, that can sprout and flourish in their own timeframes and with varying degrees of care in the garden of a person's life. Moreover, no matter how carefully cultivated, a garden is inextricably linked to and affected by the various ecosystems around it. So too, participants' identity, awareness, and empowerment experiences grew in nonlinear, variable, and embedded ways.

The current chapter represents an analytic excursion, preliminary and partial, into the lives and landscapes that participants shared. The chapter begins with an exploration of some overarching themes and tensions that arose in participants' stories; continues with a consideration of models and metaphors that I applied to identity and empowerment; and includes my reflections on the study procedures, on cultural

complexity and relational ethics, and on my personal experiences. The chapter concludes with recommendations for future research and activism. Throughout the discussion, I refer to select concepts, research, and theories from the fields of psychology, feminisms, Deaf and disability studies, and post-colonial/Global South studies. Much like the topics of identity, awareness, and empowerment themselves, my analyses of these topics have reached me as a layered, ever-changing montage of color and sound. In this discussion, I seek to offer some of these analyses from a few different angles at a particular moment in time.

### **Themes and Theory**

Participants described their salient identities and empowerment experiences in terms of the multiplicity represented in the literature—multiple dimensions and multiple manifestations. With regard to identity, participants presented some facets of their identities as developmental, and other facets, they described as intersectional sunbursts. As Burke and Stets (2009) discussed, participants shared person (e.g., sexy, modern), role (e.g., teacher, learner), and social (e.g., Christian, disabled) identities. The social identities they mentioned included Brewer's (2001) classifications: person-based (blunt and direct as a Deaf person), relational (e.g., mother in relation to daughter), and group-based (e.g., we as women with disabilities). Although one could make inferences about collective identities based on participants' group-based identities, the individual focus of participant interviews in the current study would make these identities difficult to analyze directly. With regard to empowerment, participants discussed their experiences in terms of processes and outcomes—i.e., the development of their power over time and the ways that it manifested—which was consistent with descriptions of empowerment in the

research literature (e.g., Cattaneo & Chapman, 2010; Datta & Kornberg, 2002; Hur, 2006; McWhirter, 1994; Perkins & Zimmerman, 1995; Zimmerman, 2000). Although I did not explore a specific path to empowerment, results appear to be consistent with at least the first four stages of Hur's (2006) theoretical synthesis of an iterative empowerment process, which included a sense of powerlessness in the face of material and social barriers, raising critical consciousness, joining with others to address injustices, and sharing power and empowerment with other people. The fifth stage, transforming unjust systems, is more difficult to assess. In telling their stories, participants portrayed experiences of internal and external power and control in a manner consistent with I. Prilleltensky et al.'s (2001) definition, which included having opportunities to access basic and valued material and psychological resources, make decisions and participate in their social ecologies, and exercise competence in their lives. The power-within, power-to, and power-with classifications of empowerment, as well as the power-over type of oppression (Williams et al., 1994) appeared to serve fairly well as over-arching categories, though power also appeared to manifest in some ways that transcended these categories.

The empowerment experiences most represented in participants' stories resembled Zimmerman's (1995, 2000) construct of psychological empowerment at the individual level of analysis. This phenomenon may reflect my previous reading of the research literature, individualist United States cultural influences, my interests and training as a psychologist, or something grounded in participants' stories of empowerment themselves. Zimmerman (2000) defined psychological empowerment as involving "a combination of personal beliefs of control, involvement in activities to exert

control, and a critical awareness of one's environment” (p. 49). This maps pretty well onto manifestations of participants’ power-within, power-to, and awareness of context and power. Although the construct of psychological empowerment transpires at the individual level of analysis, it is still very much grounded in the social ecology. Zimmerman (1995) described a psychologically empowered person as someone “who believes that he or she has the capability to influence a given context (intrapersonal component), understands how the system works in that context (interactional component), and engages in behaviors to exert control in the context (behavioral component)” (p. 591). The Deaf and disabled women activists in the current study certainly discussed each of these components, perhaps focusing most heavily on the interactional component—understanding how various systems work—and the behavioral component—on the actions they took to exert control or bring about change in different contexts.

Participants also cared deeply about collective empowerment on organizational and community levels. They discussed their efforts to start and sustain organizations that met Peterson and Zimmerman’s (2004) definitions of both empowering and empowered organizations—in other words, organizations that were empowering for their participating members and empowered in their abilities to improve people’s lives and make meaningful changes in their communities. Participants also aspired to achieve community empowerment. Zimmerman (2000) defined an empowered community as “one that initiates efforts to improve the community, responds to threats to quality of life, and provides opportunities for citizen participation” (p. 54). Participants sought to improve their communities and address barriers in the areas of access and inclusion; civil

and human rights; communication and coalition; education and skills training; employment and workplace issues; health care; law and policy; parenting and families; socioeconomic barriers and poverty; sports and recreation; and the overall empowerment, strength, and participation of Deaf and disabled women.

**Identity and empowerment within overlapping contexts.** Consistent with Bronfenbrenner's (1989) ecological perspective on human development and intersectionality theory (Cole, 2008, 2009; Collins, 2000; Crenshaw, 1989, 1991; Hankivsky et al., 2011), the theme of growth within context, of manifestations of identity and empowerment in constant conversation with aspects of the environment, permeated participants' stories. As participants portrayed the germination, intertwining stems, and colorful blooms of their identity and empowerment experiences, they continually referred back to the ecosystems in which they grew. They described seasons of dormancy and growth, outlining the environmental conditions under which their identities and empowerment experiences could or could not take root in the ground of their families, schools, communities, and countries. They underscored the effects of social climate, including the inclemency of prejudice and stigma and the warmth and light of encouragement and support. Their thriving depended on a combination of individual, community, national, and international cross-pollination and care. At the same time, their metaphoric gardens yielded harvests of profound beauty, healing, and nourishment that fed and helped sustain them and their communities.

The embeddedness of participants' identity stories is consistent with the identity literature. Participants' identity stories appeared to reflect theoretical models that present race, gender, disability, and deafness/Deafhood in terms of their historical

(chronosystemic); embodied (individual or organismic); interpersonal, institutional, and community (microsystemic, mesosystemic, and exosystemic); and socioeconomic, policy, and socially constructed (macrosystemic) components (e.g., Coleman et al., 2003; Davis, 2017; Garland-Thomson, 2011; Goodley, 2017; McIlroy & Storbeck 2011; Oliver & Barnes, 2012; Schriempf, 2001; Shakespeare, 2017). Thus Coleman et al. (2003) recommended taking an ecological perspective of cultural identity development in order to allow researchers “to move beyond linear explanations of human behavior” and “to think in terms of how behavior is organized by and within complex patterns of social and institutional relationships” (p. 40). Indeed, one of the first things I noticed was how participants’ identity stories were organized by and within the complex patterns of social and institutional relationships that Coleman et al. described. Yakushko et al.’s (2009) perspective on identity salience also incorporated ecological and intersectionality theories. They explained that one can have multiple salient aspects of one’s identity—just as participants described—and that “the salience of a particular aspect of one’s identity is dynamic and . . . changes with different contexts, settings, and times” (The Identity Salience Model, para. 3). Yakushko et al. suggested that attending to multiple and shifting identity saliences is useful, not only when conducting research, but also in bringing about changes within the many systems in which people live. This connection between salient identities and social action—a connection that many participants described in their stories—may represent a link between identity and empowerment with mechanisms worth exploring.

Participants’ experiences of empowerment processes and of the manifestations of their empowerment also demonstrated the contextual nature of empowerment as

described in the research literature (e.g., Cattaneo & Chapman, 2010; Cornell Empowerment Group, 1989; McWhirter, 1994; Rappaport, 1995; Sharp, 2010; Zimmerman, 1995, 2000). To paraphrase McWhirter (1994), the scope and nature of participants' empowerment experiences depended on the contexts (and their access to the contexts) within which their experiences occurred. As I. Prilleltensky et al. (2001) suggested in their definition of power and control in the context of well-being, participants particularly emphasized the importance of empowering opportunities. These opportunities and the people who facilitated them played significant roles in their empowerment and identity stories.

Participants encountered and addressed power differentials and systems of oppression in the forms of communication/information, physical access, economic, sovereignty, safety, and attitudinal barriers, which plagued them and impeded their participation throughout their social ecologies. Many researchers have also noticed the multiplicative and ripple effects that people can experience from the material and social barriers that occur in, for example, housing, families, schools, workplaces, socioeconomic spheres, law and policy, sociocultural attitudes, etc. (e.g., Evans, 2004; Mullings, 2006; I. Prilleltensky et al., 2001; Vera & Shin, 2006). The attitudinal barriers that arose in participants' stories, which appeared to include and transcend prejudice, stereotypes, and stigma, wove in and around descriptions of other barriers to their education, employment, wellbeing, and social participation. The insidious and pernicious web of attitudinal barriers surrounding Deaf and disabled women has been well-documented (e.g., Crawford & Ostrove, 2003; Keller & Galgay, 2010; Leigh et al., 2018). Many researchers, however, warn against focusing on attitudes and discourse to

the detriment of addressing the material and embodied effects of violence, poverty, impairment, and access barriers (e.g., Grech, 2011; Meekosha & Soldatic, 2011).

In addition to barriers, participants also experienced supports throughout their social ecologies. In defining principles important to the empowerment process, Speer and Hughey (1995) wrote, “social power is built on the strength of interpersonal relationships” (p. 733). Indeed, although participants mentioned helpful laws and policies, they primarily focused their stories on the microsystems of and mesosystemic relationships among families, schools, workplaces, mentorship relationships, and peer relationships, the significance of which has also been highlighted throughout research literature on human development and wellbeing (e.g., Bronfenbrenner, 1989; Chronister, McWhirter, & Kerewsky, 2004; Lyons, Smuts, & Stephens, 2001; McGibbon & McPherson, 2011; Mullings, 2006; Vera & Shin, 2006; Walsh, Depaul, & Park-Taylor, 2009; Whitson, Kaufman, & Bernard, 2009).

Speer and Hughey (1995) reviewed research that examined three instruments of social power, which they defined as the power to (a) reward or punish with superior bargaining resources; (b) construct or eliminate barriers to participation by setting agendas and defining issues; and (c) influence the myths, ideologies, and information that pervade the dominant culture. Although Speer and Hughey discussed these instruments of power solely on the organizational level and in the context of oppression, I find myself thinking of them in terms of the multilevel barriers and supports that participants encountered. In relation to the barriers, I notice how these instruments of social power—including resources, access, ideologies, and information—were wielded by individuals and institutions to much harmful effect. In terms of the supports that participants



appreciated, however, I notice more of the sharing than the exercise of social power—the use of these instruments in order to make music together, not to enforce power-over. The individual and organizational supporters in participants’ lives shared informational, financial, and other resources rather than using them to reward or punish; they joined participants in addressing and eliminating barriers by encouraging and working with participants, rather than setting agendas and defining issues for them; and they expressed encouragement, love, acceptance, and respect of participants, rather than acceding to stigmatizing cultural myths, ideologies, and information. The contextual realities of barriers and supports made a huge difference in participants’ empowerment journeys.

The crucial role that contexts played in the empowerment process leads me to suggest adding the term power-around to the types of power described in the literature. To my thinking, power-around refers to the power available to individuals and communities from the environment around them. It might involve the material and social resources they need to thrive, the inclusivity and accessibility of institutions and infrastructures, supports and compensation for all types of labor, as well as attention to wider contexts like global power imbalances and state laws and policies that protect human and ecological wellbeing. Although the importance of context is already present in empowerment literatures (e.g., Akey, Marquis, & Ross, 2000; Florin & Wandersman, 1984) I suspect that articulating a focus on power-around might provide some effective—perhaps even the most effective—inroads to power analyses, empowerment research, and activism.

**Awakening, awareness, and lifelong learning.** A major theme that flowed through participants’ accounts of identity and empowerment was awareness. Awareness

may have been the strongest theme that ran through participants' salient identities, their empowerment journeys, and the manifestations of their empowerment experiences—the theme that most clearly tied together identity and empowerment. As they shared the stories of their lives, participants demonstrated incisive awarenesses of themselves, of others, and of their environments and explicitly discussed awareness at stages of awakening, of increasing critical consciousness, and of expecting or committing to a lifetime of learning. Their salient, intersecting identities, for example, often unfolded within educational contexts, including schools, relationships with mentors or role models, and other experiences involving moments of awakening and learning, and many of the participants held salient identities of being a student, learner, or teacher. Awareness also served as a starting place and as an aspirational destination of their empowerment journeys—journeys that involved considerable awareness of the barriers and supports in their lives and in the lives of other Deaf and disabled women. When discussing the manifestations of their empowerment, participants frequently alluded to some form of awareness that underlay or guided their power within, their power to act, and their power to connect with others, and they identified the process of raising awareness among Deaf, hearing, disabled, and nondisabled people as having empowering potential for everyone involved.

The connection between identity and awareness pervades the research literature. Models of cultural and leadership identity development, for example, have tended to include considerations of internal aspects of development, such as one's increasing awareness of one's self, of one's social group, and of the wider culture and context (e.g., Downing & Roush, 1985; Glickman & Carey, 1993; Helms, 2017; Komives et al., 2006;

McIlroy & Storbeck, 2011; Myers et al., 1991; Ohna, 2004; Ossana et al., 1992; Putnam, 2005). In her studies of identity, empowerment, and learning among Deaf people in Flanders, Cameroon, and Gallaudet University, De Clerck (2016) described Deaf identity and emancipation as “learning processes set against the background of global-local interactions” (p. 1). In research with disability rights activists, Charlton (1998) wrote about “Raised consciousness . . . as an experientially evolved awareness of self” (p. 118) and discussed how it applied to the evolution of people’s person-based disability identities in particular. Charlton also defined “empowered consciousness” in terms of people’s group-based disability identities: “People see the connections between themselves and others and begin to . . . speak of ‘we’ instead of ‘I’ or ‘they’” (p. 119). Such attention to interconnectedness appears to be one way that awareness links together identity and empowerment.

Overall, the empowerment results in the current study reflected strongly Freire’s (1970) concept of conscientization—the process of raising one’s critical awareness of self, others, and ecological contexts and of how “to take action against the oppressive elements of reality” (p. 35). Conscientization arose in the research literature as a key component of the empowerment process (Cattaneo & Chapman, 2010; Hur, 2006) at individual, organizational, and community levels (Zimmerman, 2000). For example, conscientization or critical awareness made up the interactional dimension of Zimmerman’s (1995) construct of psychological empowerment. Researchers have found that increasing one’s critical consciousness can have a significant effect on one’s persistence in and progress toward achieving one’s goals (Chronister & McWhirter,

2006), which Cattaneo and Chapman (2010) have identified as important to the empowerment process.

I'd like to focus briefly on experiences of awakening, which appeared to shape early stages of participants' conscientization processes. De Clerck (2016) also identified a metaphor of awakening as something that Deaf participants experienced in relation to critical awareness, identity, and empowerment. She wrote, "Deaf signers 'wake up' by coming into contact with information on the unique linguistic and cultural characteristics and rights of their community; positive constructions of identity; 'empowered' deaf role models; and the concept of minimizing barriers" (p. 14). De Clerck connected awakening to empowerment by considering "the 'awakening' of the deaf community" to be "a clear protest" and an explicit call to "hearing citizens and institutions" to "adapt their learning process to extend emancipation and equality sincerely to non-hearing fellow citizens" (pp. 25-26). In other words, she found that waking up to self-awareness and to the awareness of other people and the environment helped initiate positive Deaf identities, Deaf empowerment, and awareness among hearing communities.

**Values, beliefs, and spirituality.** The theme of awareness was not limited to the informational plane of knowledge and skills but included emotional and spiritual components as well. Participants learned about and cherished the values and beliefs that gave their lives purpose and strength. For many, their awareness of or faith in God was an important aspect of their identities and a source of their power. Some held fast to their love of family or their convictions about social justice. Regardless, participants seemed to emphasize the values that grounded them in the present and guided them onward.

The topic of values was mentioned in the identity and empowerment literatures. I. Prilleltensky and Nelson (2009) defined values as “principles and practices that confer benefits to individuals, relationships, and the collective” and argued that “values should guide the enhancement of human wellbeing” (p. 133). One can infer from I. Prilleltensky and Nelson’s definition that values might guide identity and empowerment processes insofar as these processes are related to wellbeing. Identity process theorists have suggested that an individual’s value priorities can moderate the relationship between identity motives—the desirable end states for identity processes—and the centrality—importance, emotional evaluation, and everyday enactment—of a given identity in the individual’s life (Bardi, Jaspal, Polek, & Schwartz, 2014). Interestingly, other identity researchers have classified values as identity attributes in and of themselves (e.g., Stirratt et al., 2008). Similarly, empowerment researchers have identified the presence of values as one “wellness-enhancing” factor that can increase experiences of power and control (I. Prilleltensky et al., 2001, p. 149), while others have designated empowerment itself as a value orientation (Perkins & Zimmerman, 1995; Zimmerman, 2000). Although we may not understand exactly how, the likelihood that values represent another potential link between identity and empowerment seems high.

Religion and spirituality appeared to be both an origin and an expression of participants’ values and beliefs. Contemporary literatures on spirituality consider spirituality to involve a fully integrated approach to life; a quest for the sacred; a search for meaning, which extends to understandings of identity and human development; perspectives on thriving; self-reflection; and interconnectedness (Sheldrake, 2012). Within their Christian, Muslim, Buddhist, Hindu, and secular traditions, participants

appeared to orient to and practice spirituality in all of these areas. In the context of discussing the wellbeing of women of color in the United States, Comás-Díaz (1994) discussed how spiritual beliefs and practices can be important to many women of color as part of defining their individual and collective senses of self (identity) and as sources of personal strength (empowerment). With regard to identity, Myers et al. (1991) argued that spiritual development is an essential part of identity development. Drawing from Afrocentric indigenous traditions, Myers et al. proposed an identity development model that traced the process of “people coming to know themselves more and more fully as spiritual-material beings” (p. 57) in continuous interaction with their sociocultural environments.

Anzaldúa (e.g., 2015) offered the concept of *conocimiento*, a concept that seems to tie together participants’ experiences of critical awareness, values, spirituality, motivation, creativity, and empowerment. Anzaldúa defined *conocimiento* as expanded awareness that includes the spiritual knowledge “that we’re connected by invisible fibers to everyone on the planet and that each person’s actions affect the rest of the world” (1. Let us be the healing of the wound, para. 20). She outlined the path of *conocimiento* as leading to “awakening, insights, understandings, realizations, courage, and the motivation to engage in concrete ways with the potential to bring us into compassionate interactions” (1.1 Remolinos, para. 3). *Conocimiento* also underlies what Anzaldúa called “spiritual activism,” which she defined as an amalgam of spiritual practices, such as “contemplation, meditation, and private rituals,” and the “technologies of political activism,” which include “protests, demonstrations, and speakouts” (1.1 Remolinos, para. 1). She expanded on this description by explaining that *conocimiento* “advocates

mobilizing, organizing, sharing information, knowledge, insights, and resources with other groups” (7. shifting realities .... acting out the vision or spiritual activism, para. 11). The practices that Anzaldúa described would certainly be familiar to many of the participants in the current exploration. Also, reminiscent of participants’ self-care and spiritual activities, Anzaldúa believed that “conocimiento is reached via creative acts—writing, art-making, dancing, healing, teaching, meditation, and spiritual activism—both mental and somatic (the body, too, is a form as well as site of creativity)” (The Journey: Path of Conocimiento, para. 4). Ultimately, Anzaldúa’s conocimiento and empowerment were one in the same: she wrote, “Power comes from being in touch with your body, soul, and spirit and letting their wisdom lead you” (7. shifting realities .... acting out the vision or spiritual activism, para. 6).

### **Thematic Tensions**

For the most part, the themes that arose in participants’ stories were not straightforward or simple but involved dynamic tensions. Just as Freire (1970) wrote, “themes are never isolated, independent, disconnected, or static; they are always interacting dialectically with their opposites” (p. 101). In participants’ stories, many themes had at least one counterpart, and experiences of empowerment seemed to arise when the themes were present and in conversation with one another: e.g., being normal and different; having personal agency and an interdependent community; working hard and accepting life as it is; adapting to, advocating within, and resisting oppressive systems or structures. Participants’ capacities to hold intentions that were in tension or to dance in the spaces between contrasting experiences, aspirations, and approaches appeared to be an important theme in and of itself.

A complex use of dialectics and theoretical integration is strongly present in literatures of disability studies, identity, and empowerment. Scholars working in critical disability studies—as well as in new material feminisms—blend paradigms that acknowledge the reality of the body, of the built environment, and of linguistic and other social representations/constructions (e.g., Garland-Thomson, 2011; Goodley, 2017; Schriempf, 2001; Siebers, 2008). With regard to identity, Seaman et al. (2017) argued that taking a dialectical approach to addressing the tensions and contradictions of various identity theories could generate new research questions and yield theoretical integration. Perkins (1995) made a similar argument for using dialectical analyses to make more effective use of empowerment theories. In his work on education, empowerment, and liberation, Freire (1970) employed important dialectics of (a) the material world and the world of social institutions and representations and (b) critical consciousness and praxis. I. Prilleltensky and Nelson (2009)—critical psychologists who have studied power, control, oppression, and liberation—expanded on the work of Freire and others to describe what they called “a critical paradigm of knowing” (p. 131). They described this paradigm, at once fractured and integrated, as including critical constructivist and postpositivist traditions and incorporating community-based, participatory, and action-oriented methods. I. Prilleltensky and Nelson borrowed the term “frenetic social science” (p. 131) to describe this complex, messy, and social-justice-driven process. I embrace this notion of a frenetic social science as I seek to identify and analyze some of the interactive themes in the current study.

**Normativity and nonconformity.** A thematic tension within participants’ identity stories appeared to involve their strategies of both covering and claiming



disability—of emphasizing normality and alterity. When and how would they fit in, and when and how would they stick out? Their strategies appeared to advance positive identity and empowerment individually and in combination with one another. For example, participants lived or performed normality and de-emphasized their disabilities or their differences in certain situations and developmental moments. This strategy corresponded with manifestations of empowerment, such as building confidence in their skills, seeking to change social stigma and low expectations, and navigating systems and hierarchies to advance social justice. In other spaces and times, participants accentuated or lived proudly their Deaf, disabled, or divergent identities. The strategy of emphasizing alterity corresponded with manifestations of empowerment, as well, such as building confidence in themselves and their self-worth, seeking to change social stigma and low expectations, expressing truth to power, serving as collaborative leaders, and seeking to empower others. While covering, claiming, and even performing difference may appear to be contradictory strategies, participants' tendencies to do all of the above to varying degrees in different circumstances seemed to open a way to various empowerment experiences.

The concept of normalcy plays a significant role in Deaf and disability studies. Davis (2017) explained that norms influence every part of contemporary life and asserted that the construction of normalcy has created the “‘problem’ of the disabled person” (p. 2). Davis dated “the coming into consciousness in English of an idea of ‘the norm’” back to the time of industrialization in the mid-1800s (p. 2). Due to the joint influences of statistics and eugenics, the meanings of average and ideal became entangled, and concepts of normality, normalcy, and norm became prescriptive as well as descriptive.

By extension, people whose body-minds deviated from the norm were identified, defined, criminalized, and dehumanized. Although “normality has been deployed in all aspects of modern life as a means of measuring, categorizing, and managing populations,” it has also become a means of “resisting such management” (Baynton, 2017, p. 19). The hegemony of normativity and the related ideologies of whiteness (Smith, 2004) and ability (Siebers, 2008) provide an important backdrop to the complicated tensions that participants expressed around formulating and living certain identities and empowerment experiences.

The thematic tension of living in and between (at least) two worlds—navigating normative and diverging realities and finding sites of resistance—arises in critical race, postcolonial, Deaf, and disability studies. Concepts of double consciousness (Du Bois, 2014), cultural pluralism (Comás-Díaz, 1994) *mestiza* consciousness and *nepantla* (Anzaldúa, 2015), hybridity and diaspora spaces (e.g., Gandhi, 1998), and half and half (Titchkosky, 2011) pluck at this tension. One or more of these concepts have been applied to women of color (e.g., Anzaldúa, 2015; Collins & Bilge, 2016; Comás-Díaz, 1994; Lee & Sum, 2011), Deaf people (e.g., Emery, 2015; Ladd, 2008), and disability communities in the Global South (e.g., Goodley, 2017; Grech, 2015). Without diving into the myriad definitions, elaborations, and contestations of these terms, I would like to gesture toward how they might apply to the current study.

The participants in the current exploration lived half in and half out, a part of and apart from, and with multiple and intermingled consciousnesses of Deaf and hearing worlds, disability knowledges and normative pressures, ciswoman experiences and patriarchal forces, and cultures of local communities and of the metropole. The

experience of living in and with multiple, blended, and changing material and cultural demands is often logistically complicated and psychologically exhausting (e.g., Anzaldúa, 2015; Comás-Díaz, 1994; Du Bois, 2014) because it “permanently fixes the coloniser in the psyche, body and space of those it colonised” (Grech, 2015, p. 16). Participants mentioned doubting themselves, experiencing exhaustion and stress, feeling alone and misunderstood, and having a range of difficult emotions. At the same time, living a complex, blended, and in-between experience can also be a valuable position from which to generate situated knowledges, resist colonial or normative indoctrination, create, and bring about transformation (e.g., Anzaldúa, 2015; Gandhi, 1998; Grech, 2015; Lee & Sum, 2011; Titchkosky, 2011). In the context of discussing black women’s activism in the United States, Collins (2000) wrote that even when black women “appear to conform to institutional rules, they resist by creating their own self-definitions and self-valuations” (p. 205). Likewise, participants created and lived their complex self definitions and challenged social expectations by being normal and relatable, being disabled and relatable, demonstrating unexpected skills, holding up a mirror to stigma, shattering normative assumptions, and offering unique and creative perspectives. In other words, their examples of liminal living and shifting their positions demonstrate how the personal can be political and how dominant cultures can be infiltrated and changed.

**Agency and communion.** Participants pursued experiences of personal authority and of supportive, interdependent communities. Their identity and empowerment journeys were replete with the needs to express themselves authentically, make decisions freely, act skillfully, belong, get along, and participate fully, as well as with the tension of pursuing all of these needs. Manifestations of participants’ empowerment revealed an

intermingling of individual and communal focuses, often within the very same experience. For example, experiences of decision making or of traveling often involved motivations both to pursue individual sovereignty and foster social connectedness. As with covering and claiming disability, participants' movements toward personal control and toward affiliation with others resembled a vibrant dance—a choreography of empowerment.

Academic conversations about agency and communion have taken a variety of forms in relation to empowerment. Some authors have equated power and empowerment more strongly with individual control or agency than with community (refer to Riger, 1993; Wiggins, 1991). Participants' empowerment experiences, however, incorporated both individual and community orientations and motivations. Their multisystemic focuses resembled I. Prilleltensky's (1997) emancipatory communitarian approach, which he also differentiated from a more individualistic empowerment approach. I. Prilleltensky explained that people aspiring to an emancipatory communitarian approach focus on the wellbeing of individuals and of communities; draw from local and grounded knowledges; consider individual rights alongside social responsibilities; take action to address social, economic, and political sources of oppression and disempowerment; and promote a system of values that includes caring, compassion, self-determination, human diversity, collaboration, democratic participation, and distributive justice. For example, when participants mentioned social and family restrictions on the education, employment, and general mobility of Deaf and disabled women and girls, they asserted the importance of individual sovereignty or emancipation. When they described instances of competitiveness within or across Deaf and disability communities, participants (a)

emphasized the importance of a diverse and collaborative community over the concerns of individual actors and (b) expressed caring and compassion for the experience of lacking social-material resources, which they believed contributed to community fragmentation in the first place.

Researchers and theorists have considered a number of concepts related to personal sovereignty—concepts that each take a different angle on agency. Many of these concepts—*independence, autonomy, personal control, competence, self-determination, self-efficacy, etc.*—have been linked to empowerment (e.g., Charlton, 1998; Desai, 2010; Finfgeld, 2004; Hur, 2006; Zimmerman, 1995, 2000). Such concepts involve multiple definitions and can rest upon individualist assumptions, and thus researchers have debated the appropriateness or applicability of these concepts to various populations and cultures (including disability cultures) across the world (e.g., Collins, 2000; Crawford & Ostrove, 2003; Kittay, 2017; Siebers, 2008; Syed, 2010). Bandura (2002), for example, encouraged researchers to consider agency in terms of personal, proxy, and collective types of agency; to account for personal and collective efficacy beliefs; and to apply these concepts together in relation to cultural contexts. Meekosha and Shuttleworth (2017) defined autonomy as “*emancipation from hegemonic and hierarchical ideologies that structure personal consciousness, representations, social relations and practices in everyday life*” (p. 180) and contended that the concept of autonomy—as well as that of social participation—must remain flexible and amenable to history and context. Such flexible, multifaceted, culturally embedded definitions of agency, self-efficacy, autonomy, and so on appear most appropriate to discussions of empowerment among the Deaf and disabled women activists in the current exploration.

Interdependency—as an angle on communion—is an important concept in disability studies. Although encouraging education, skill-building, and the removal of access barriers is very important to what some disability activists have called independent living (e.g., Charlton, 1998), ultimately, interdependency structures all human lives. Kittay (2017) argued that any adequate theory of social justice must account for interdependency and that “the way to include all people with disabilities is to focus on the nature of human beings as vulnerable to inevitable dependency, the care of inevitable dependency, and the inextricable interdependence of humans on one another” (p. 306). Not only would this stance include many more disadvantaged and vulnerable peoples than our current theories based on the ideology of ability (Siebers, 2008), but Kittay maintained that once we accept the “inevitability” and “inextricable nature of our interdependence,” we can perceive it “not as an impediment to living well, but as a source of value: a source of connection; an occasion for developing our capacities for thought, empathy, sensitivity, trust, ingenuity, and creativity” (p. 310).

**Effort and acceptance.** The strategies of working hard and of accepting one’s self, other people, and life circumstances also seemed to function as an ongoing dialectic that engendered empowerment. Participants expended significant effort as they pursued their education and training, actively practiced and built inner strength, taught and trained others, served as role models, navigated inaccessible systems, expressed themselves, resisted injustice, practiced collaborative leadership, and sought to empower new leaders—all of which contributed to or actualized their empowerment experiences. They also acknowledged that other people’s behavior and life circumstances were often out of their control, accepted the reality of many access and attitudinal barriers and gradual

progress, and sometimes, went as far as embracing life's difficulties as part of the learning experience. All of these strategies played a part in their empowerment experiences as well. On one end of the effort-acceptance dimensions, participants had to be careful not to overwork and overtire, nor could they practice acceptance to the point of complacency. Instead, they seemed to employ shifting combinations of working and resting; of grasping and releasing; of resisting, allowing, and embracing life's circumstances as their journeys of empowerment unfolded.

Participants' movements between, in, and around effort and acceptance reminds me of the dialectic of acceptance and change described by Linehan (1993). Linehan, a woman-identified psychologist in the United States, has self-identified as having borderline personality disorder (Carey, 2011) and has described her experiences as a psychiatric consumer/survivor/ex-patient. She developed dialectical behavior therapy (Linehan, 1993), the most fundamental dialectic of which is that of acceptance and change. Accordingly, participants' strategy of working hard is, at essence, a strategy of change: participants worked hard to (a) adapt or change themselves to fit into an inaccessible environment and (b) change the environment itself. Participants also practiced what Linehan and others have called radical acceptance (Carey, 2011). Brach (2003) described radical acceptance as a combination of mindfulness and compassion that she defined simply as "the willingness to experience ourselves and our life as it is" (Prologue, para. 12). For participants, this willingness seemed to be an important piece, not only of experiencing empowerment, but of developing positive Deaf and disability identities.

**Adaptation, advocacy, and resistance.** Here I would like to drill down into the forms of effort that participants described as part of their empowerment processes. As they worked hard, participants made choices about how to exert effort in their lives: When would they adapt to an inaccessible world, advocate for change, or resist injustice? Each of these approaches demanded a significant amount of time and energy. In Chapter VI, I grouped participants' adaptation strategy with acceptance because it seemed to involve an element of surrender to a sizable and not-always-controllable reality. At the same time, I want to acknowledge that adapting to an inaccessible or inhospitable environment takes work and can exhaust a person just as advocacy and resistance can. Participants engaged in adaptation by planning and preparing, factoring in the extra effort that they would need to expend, using prosthetic/adaptive devices and technologies, and employing creative problem solving. All of these adaptation strategies helped lay the groundwork for their advocacy and resistance efforts. Sometimes, rather than adapting, participants chose to advocate for change. Their advocacy efforts involved fostering relationships and community, engaging in self-advocacy, and pursuing social justice in a multitude of ways. At other times, participants chose to resist injustice. Some of their resistance strategies included challenging cultural perceptions and expectations and expressing truth to power.

In terms of connecting these results to the literature, I would like to focus particularly on resistance in relation to empowerment. In addition to defining power-over and power-to, Hollander and Offerman (1990) identified power-from as an important type of power. They defined power-from as "the ability to resist the power of others" (p. 179). Although the majority of participants' empowerment experiences involved moving



toward other people and toward awareness and advocacy projects, in some times and spaces, they needed to move against people or systems. Being able to say, “No you can’t” or “No, this is unacceptable” appeared to be as important, in certain instances, as being able to say “Yes, I/we can” or “Yes, I accept this.”

### **Intersecting Identities and the Contours of Empowerment**

To what extent do the broad themes and tensions that surfaced in the current study suggest answers to the question: How do deaf and disabled women activists experience intersections of their identities and empowerment? Given the complexity of paradigms, theories, and levels of analysis present in studies of social ecologies, identity development, empowerment, and intersectionality, I am reluctant to add more scholarly definitions to the fray, especially as part of my first attempt to study these concepts. I will, however, reflect briefly on a burgeoning model of intersecting identities that I used to think about participants’ stories and on a general description of empowerment.

Including and analyzing so many salient, intersecting identities within each participant’s empowerment story was challenging, even with my fairly minimal interpretations. I developed a basic model or organizational system to help me organize and report results. As I considered how identities or aspects of identity generated and organized each other, developed and interacted over time, and intersected and overlapped with important contexts at key moments in participants’ stories, I found it helpful to create a few maps to help me trace how identities seemed to manifest and function. I’ve included the identity maps I made of Charity’s, Lizzie’s, and Maru’s stories in Appendixes K-M. In these identity maps, the colored lines represent identities and how they moved and interacted with each other in a snapshot of a participant’s identity story.

The shaded ovals symbolize experiences or ecological contexts that influenced a person's identity development, and the shaded ovals with colored borders depict salient identities within a particular context or moment in time. The colored lines that move through unshaded spaces denote a participant's ongoing identity development outside of the contexts that she mentioned in her story. Further exploration and use of this organizational and identity mapping system might elucidate the potential usefulness of this method in tracking multiple, intersecting salient identities in people's stories.

The general definition of empowerment that I used at the beginning of this exploration needs a little alteration in light of the results that emerged. In general, participants' empowerment processes and experiences involved (a) developing self-awareness and inner strength (power-within), the power to share information and collaborate with others (power-with), and the power/freedom to raise critical consciousness, make decisions, and act to effect change (power-to); (b) considering individual power (power-within and power-to) in conversation with collective power (power-with) while minimizing domination over others (power-over); (c) interacting with ecological systems and structures that are responsive to their needs, that grant access to important resources, and that allow for full participation (power-around); (d) resisting oppressive systems and structures (power-from); and (e) thinking and acting carefully in the attempt to empower others (power-for). These empowerment processes appear to connect with participants' intersecting salient identities through participants' social locations, conscientization processes, and value orientations.

## Reflections on the Study

**Limitations.** The current study involved limitations in its design and implementation. Because the purposes of the study were both to cast a wide net and to dive deeply—to explore the intricate stories of a large number of participants with a range of experiences from a variety of backgrounds—the current study, by its very nature, lacked succinctness. Within the exploratory nature of the study, however, a few specific limitations emerged as most prominent: these included the digressions from the constructivist grounded theory guidelines, the languages in which the interviews were conducted, the access and communication barriers that arose during the follow-up portion of the study, additional content important to the study of identity and empowerment that I did not adequately investigate, and the dubious applicability of the study to the participating communities.

As noted in Chapter III, the design of the study deviated from constructivist grounded theory guidelines in some significant ways. First, I limited my sample to participants who attended the 2013 WILD program rather than seeking additional participants based on an ongoing analysis and saturation of the data. Second, the full and busy schedule of the WILD program allowed the participants and me little free time to conduct interviews. Therefore, collecting and analyzing the initial interviews simultaneously was impossible, a design limitation that restricted the iterative potential of the research. I was unable to ground the questions of each progressive interview in the data that came before it, and consequently, my preconceptions and interpretations may have played a particularly prominent role in the themes and categories that emerged. The lack of responsiveness or recursiveness in the research design and procedures also

detracted from the degree that I could implement values of community-based participatory research (e.g., Leavy, 2017).

The languages used in composing and conducting the interviews represented another limitation of the study. Participants signed and spoke at least 24 languages, the vast majority of which did not play a role in our interviews or correspondences. I composed the interview questions in English and intermediate Spanish and worked with ASL, French, and Spanish interpreters. Most of the interpreters were certified professionals, and others were noncertified volunteers who generously offered their support. In any case, the language and cultural nuances and the multiple layers of communication—such as the interpretation from participants’ national sign languages to ASL to English and back again—left a great deal of space for misinterpretations and cultural transgressions.

My use of English, Spanish, ASL, and French in data collection not only excluded the languages and dialects in which some participants felt most comfortable communicating but also entailed colonial histories and neocolonial practices. These languages of the British, Spanish, United States, and French empires involve, to varying degrees, backgrounds of diminishing and derogating indigenous perspectives rather than amplifying and honoring them. One might argue that ASL has the least colonial history and that working with CDIs was a particular strength of the current study. Some scholars, however, have pointed to the spread of ASL and hearing signed codes of English to countries in Africa and Southeast Asia by American missionaries and teachers, arguing that this spread has constituted a form of sign language oppression in that it has pushed out and resulted in the deaths of many indigenous sign languages (Bauman, 2008; Leigh

et al., 2018). The Deaf interpreters who shared their expertise certainly had personal experiences and professional training that prepared them to facilitate “comprehension and interaction in a wide range of visual language and communication forms influenced by region, culture, age, literacy, education, class, and physical, cognitive, and mental health” (National Interpreter Education Center, 2018, What is a Deaf Interpreter? para. 1).

Although the support of these CDIs strengthened the study by helping me attune to the Deaf-same aspects of Deaf culture, it did not necessarily help me understand or navigate Deaf cultural differences, especially after participants’ stories were interpreted into ASL and then English.

The existence of many technological access and communication barriers greatly impeded my close contact with participants after they returned to their home countries and thus posed a significant limitation to the implementation of the study. Some participants had limited internet connection in their homes and communities. I also encountered difficulties keeping in touch with participants on my end, as I am someone who depends on screen-reading technology and who has minimal experience navigating social media with my screen reader. I fear that the extra time and effort that I needed to expend in order to stay in touch deterred me from engaging in the kind of regular communication that I had imagined and hoped for.

These communication barriers were particularly noticeable as I sought to conduct follow-up interviews with Deaf participants. In order to communicate in real-time, we depended on two simultaneous three-way video calls—one that connected the participant, CDI, and me, and the other that allowed me to talk with the CDI through a video relay service. If this system were not complicated enough, the degree of lighting and the

fluidity of the video connections (or lack thereof) also had a significant impact on the visibility of sign languages and thus on our communications. Even when the technology cooperated—which was maybe half the time—the fluidity of our conversation and the time needed to cover the interview questions differed greatly from other follow-up interviews.

Another limitation was that I did not initiate explorations of some important topics to the study of identity and empowerment; I hesitated to open topics that might be too personal or politically dangerous. For example, I did not include questions in my interview plans about sexual identity, authoritarian regimes, experiences of violence, political unrest, or anything that I believed to be traumatic or illegal in participants' countries. I made these decisions because I wanted to honor the courage of so many participants who chose to use their names and because I was concerned that I could put participants at emotional, social, or political risk by exploring such personal-political topics. When participants initiated discussion of their sexual identities, experiences of violence, or risky political opinions, however, I asked follow-up questions and elicited details that greatly enriched the pieces of participants' stories that I was able to share. Although I would probably make the same decisions if I were to conduct this dissertation again under similar conditions, I believe that omitting topics that are so central to participants' intersecting identities and empowerment experiences was a profound limitation of the research.

Finally, I wonder about the potential applicability of this dissertation to MIUSA and to the Deaf and disabled women activists who participated in this exploration. Although I utilized aspects of community-based participatory research, I did not achieve

a full collaboration process with community members/participants. I asked MIUSA staff, who work in the Eugene community, to guide the initial formation of the study's purpose and research questions, but the university policies did not allow for some of the more program-evaluation-oriented questions that we proposed. Based on these program evaluation questions, I collected but did not analyze data specific to the WILD program—data that are not reported in this manuscript. Even with these additional data, I remain unconvinced that MIUSA will benefit in a concrete and practical way from this dissertation given the breadth of the results, the lack of analyses related to program evaluation, and the time required to complete the project. Similarly, although I invited participants to engage in member checks of their interview transcripts and to review the results chapters, they themselves were not involved in posing the research questions and thus may find some aspects of this research to be more relevant or irrelevant to their lives than others. Moreover, I believe that I fell into the trap—noticed by so many researchers before me (e.g., I. Prilleltensky, 1997; Riger, 1993)—of focusing more on individual empowerment than on the collective empowerment of the Deaf and disability communities that participants worked so hard to serve. Relatedly, my training has better prepared me to investigate aspects of empowerment in experiential and sociocultural realms than in realms of economics, law and policy, and international relations, which are absolutely crucial to empowerment studies.

**Reflections on cultural complexities and relational ethics.** The process of conducting this dissertation was so wonder-full and complex that my head spun with all of my experiences and reflections, particularly with the kaleidoscopic cultural components and the exigencies of psychopolitical validity (Morsillo & I. Prilleltensky,

2007; refer to Chapter III for a description). My intention was to remain aware and respectful of power dynamics and of cultural differences throughout my interviews, observations, and interactions. At the same time, I shared participants' empowering beliefs that each moment and each mistake was a learning opportunity. The content of my reflections could span the length of another dissertation, but in brief, I'd like to offer a few thoughts on my work toward cultural competence and relational ethics.

Inevitably, participants and I made assumptions about each other over the course of the study. I, for example, conjecture that many participants may have preferred to express themselves during the interviews in languages other than English, Spanish, ASL, or French, but I did not ask every participant about her preferences directly. I also held varying degrees of historical and sociopolitical awareness about the countries and communities from which participants came, and my interview questions and the ways that I asked them certainly reflected my range of awareness. In terms of participants' narratives, I imagine that the participants were conscious of how they presented themselves during interviews and shared the aspects of their lives that they believed were most desirable or useful for me to know. I noticed, for example, that participants with religious or spiritual identities other than Christianity seemed to share less about these identities and spiritual practices than their Christian peers. Their reticence may have reflected individual differences, cultural narratives, or religious politics in their particular countries; it may also have reflected their perceptions of the dominance of Christianity and the bigotry—for example, Islamophobia (e.g., Arredondo, Tovar-Blank, & Parham, 2008)—that exists toward people of non-Christian religions in the United States.



Amid our various assumptions about one another and potential cultural miscommunications, I believe that participants and I built meaningful and beautiful bridges. We shared variations of disability, woman, and activist identities and expressed a deepening care for one another. The scaffolds of our relationships, shared identities, and care supported the bridges that we built and seemed to hold fast through any miscommunications that took place.

Wertz et al. (2011, p. 354) wrote about ethics in qualitative research as a “relational craft” that goes beyond “applying abstract principles and procedural rules”—such as the ones described in Chapter III—to include “ongoing, flexible judgments and creative responses to the complex challenges that arise in research situations.” The preponderance of flexible judgements and creative responses that guided the ethical dimensions of this dissertation was mine, and thus I bear the responsibility of my decisions, actions, and inactions.

The most prominent relational-ethical question that I asked myself regularly over the course of this project was: How do I ethically and effectively navigate the spaces between being a researcher and being an advocate? This question took many forms. For example, when and to what extent could I be an advocate in relation to participants by locating resources, reviewing applications to educational and training programs, serving as a professional reference, offering emotional support, spreading the word about fundraising campaigns, making financial contributions to individuals or organizations, or facilitating travel to the United States? In addition to my adherence to APA (American Psychological Association, 2017) ethical guidelines, my varied and situated answers to these questions were influenced by my values, knowledge, skills, schedule, health,

emotions, intersectional identities, social locations, power, privileges, etc. In short, I offered my time, energy, and conversation whenever I could; I found that I did not have the power or professional network to help participants navigate difficult systems; and I postponed my plans to make any financial contributions until after my graduation. By writing this dissertation, I also encourage the reader to become an advocate by getting involved in whatever way possible in supporting the rights and wellbeing of Deaf and disabled women and girls across the world.

**Personal reflections: another paradox of empowerment.** In addition to considering the paradox of empowerment—to what extent can we truly empower other people without exercising a power-up position or emphasizing this power imbalance? (refer to Chapter II)—I noticed another paradox over the course of my research. Like De Clerck (2016), “I was confronted with the paradox of undertaking research on deaf [and disability] empowerment while not actually feeling empowered” (p. 175, brackets mine). I experienced a plethora of access barriers as I searched for books and research articles, converted readings into accessible text that my screen-reading software could recognize, conducted follow-up interviews and maintained ties with participants using a variety of platforms and technologies, coded the transcripts, grouped the codes into categories, located quotes that fit the categories I wanted to discuss, managed references in APA format, and sought out and scheduled time with sighted assistants. Attitudinal barriers were also a part of my general experience in and outside of graduate school. Throughout the entirety of the dissertation project, I grappled with chronic illness, pain, and fatigue. My confidence waned. I felt discouraged, disconnected, and disempowered and found myself turning to participants’ stories for guidance, hope, and a sense of community.

Like participants, I oriented to my values of awareness, learning, and social justice, at which point, I faced the challenge of trying not to judge the discrepancies between my values and my ability to live them. I was taking such a long time with the dissertation as MIUSA and participants waited eagerly for results. Although I managed to pass along some resources to participants and offer some consultation around their applications, projects, and personal conundrums, I did not feel that I was meeting my social justice value of power sharing—a value that is important to community-based participatory research (Leavy, 2017), especially when the research itself is on empowerment (e.g., Zimmerman, 2000).

De Clerck (2016) wrote about her feelings of disempowerment as a Flemish Deaf woman in the process of conducting her dissertation:

I was . . . unable to do what I was supposed to do as a deaf scholar—share resources, lead, contribute to the community, and give back the knowledge and wisdom deaf people had passed on to me. . . . It went against my beliefs. . . . When I was not able to engage in sharing with the deaf community and to contribute as an active member, I experienced an existential conflict. The entire process of writing a doctoral dissertation that had cultural import in the community and had raised expectations of giving back suddenly lost meaning. Even my sense of who I was as a person began to become lost. (p. 198)

When I first read her words, I felt as though De Clerck had expressed the conflict of my heart. I also felt grateful that she was willing to share her experience so that a blind doctoral student living an ocean and a continent away could feel accompanied and understood.

Like De Clerck (2016), I tried to draw strength from my research and what I was learning from participants. To build power-within, I scraped together self-care and spiritual practices. I worked to acknowledge my privileges with gratitude. I used strategies of working hard and practicing acceptance, the latter of which has been

particularly difficult for me in relation to my health. I exercised power-to by advocating for myself when I could and by sticking with the dissertation. Although the support of my family, friends, and research assistants offered me something of a safety net when my hope and confidence plummeted—as did reading the works of Deaf and disabled scholars—the lion’s share of my internal strength sprang directly from my interactions with participants’ words. In their words I “found an unexpected gift at a moment when I needed it most: a treasure of strengths” (De Clerck, 2016, p. 201).

My struggle to engage with my own empowerment processes over the course of the dissertation has led me to think more about paradoxes of empowerment. To what extent can basing research in communities of Deaf and disabled women truly be empowering when so many contexts remain disempowering? How can research on empowerment go beyond inclusion and participation to facilitate empowerment processes and experiences among the Deaf and disabled women who co-create the research?

Although I am a novice at researching and understanding larger systems and structures, it is clear to me that, “for systemic problems, systemic solutions must be found” (Charlton, 1998, p. 165). So often I have felt utterly stymied by systems—as I advocated at the university, sought medical support, listened to participants and therapy clients, and observed the creation and renewal of unjust policies and practices in this country and across the world. From beginning to end of this dissertation, I ached to learn, to know more—more about histories, international relations, economics, policy processes, and the various mechanisms and manifestations of domination and oppression. Ultimately, I ached to learn how to challenge and change oppressive systems. The next

time I embark on a research project, I will be sure to collaborate with other scholars and activists who can offer different perspectives and more of the knowledges that I lack.

### **Recommendations for Future Research**

Future directions for research in the areas of identity and empowerment are as numerous and complex as the topics themselves. Future research could be theoretical, applied, qualitative, quantitative, exploratory, intervention based, and preferably some compilation or combination of many different epistemic and methodological approaches. More specifically, some potential directions for future research on identity and empowerment might involve (a) inclusion of and full collaboration with Deaf and disabled women from the Global South at all stages of research; (b) the design and evaluation of potential models for assessing and conceptualizing intersectional identities; (c) a greater focus on the empowerment of Deaf and disability activist organizations; (d) the continued design of culturally relevant, multi-dimensional surveys of empowerment on individual, organizational, and community levels; and (e) exploration of and adherence to different knowledge traditions and methodologies.

**Involve Deaf and disabled women from the Global South.** Future research could involve full collaboration with Deaf and disabled women from specific communities, particularly those in the Global South that are too often affected by scientific discourses that do not include them (e.g., Grech, 2011, 2015; Huygens, 2009; Meekosha & Soldatic, 2011; Titchkosky & Aubrecht, 2015). To begin with, the number of Deaf, disabled, indigenous, and woman-identified researchers of color in academia is alarmingly low in the United States, and universities can be much more proactive in recruiting, training, and hiring these underrepresented students and faculty (e.g., Kosanic,

Hansen, Zimmermann-Janschitz, & Chouinard, 2018; Lund, Andrews, & Holt, 2014; Weber, 2006). Second, scholars have discussed empowerment as consisting of processes and outcomes (e.g., Cattaneo & Chapman, 2010; Hur, 2006; McWhirter, 1994; Zimmerman, 1995, 2000) that are inextricable from specific, local communities (e.g., Cornell Empowerment Group, 1989; Desai, 2010; Sharp, 2010) and identity as being deeply imbedded in ecological contexts as well (e.g., Coleman et al., 2003; Yakushko et al., 2009). Thus focusing in on specific communities—whether they be in the Global North or South—might bring researchers and activists closer to unraveling the intricacies of individual and social identity and of individual, organizational, and community empowerment as they manifest in particular contexts. In addition to focusing on specific communities, Deaf, hearing, disabled, and nondisabled researchers can utilize community-based participatory research methods (e.g., Leavy, 2017), which involve methods that are particularly congruent with goals of empowerment (e.g., Morsillo & I. Prilleltensky, 2007). The WILD participants modeled just such participatory research when they held focus groups in their communities to identify and design helpful services. Finally, the use of constructivist grounded theory (Charmaz, 2006, 2011) in its intended form is another way that future research could include Deaf and disabled women activists in the design of research questions and in the story-ing of research results. Such methods could help researchers seek the grounded knowledge of I. Prilleltensky's (1997) emancipatory communitarian approach.

**Create models for assessing and analyzing intersecting identities.** I also recommend that future research continue to create and test models that aid in investigating and conceptualizing a person's many, intersecting identities. Such models

might help in illustrating the presence and mutual influences of several identities at once and might help researchers ask and pose answers to more complex questions. How and at which points in a person's life story might identities augment, support, conflict with, or create tension among one another? To what extent might one's identity development along a number of different dimensions correspond with one's internal sense of or external measures of empowerment? How do a person's privileged and oppressed social identities influence one another and the empowerment process? To what extent and under what circumstances can altering the performance of one's identity—i.e., covering, claiming, or exaggerating normativity or difference—be empowering or disempowering? When engaging in activism within a diverse community, how might organizations or programs consider and support the empowerment of unique individuals who have a tapestry of salient, intersecting identities?

**Focus on organizational empowerment.** The continued research of organizational empowerment might be of particular use and interest to Deaf and disabled activists across the world. Some scholars have expressed the belief that “empowerment is achieved only through organization” (Speer & Hughey, 1995, p. 735), and in this dissertation, participants described ardent desires, hopes, and dreams about developing and sustaining their activist organizations. Learning more about the organizational stories of Deaf and disabled women could add greatly to our understanding, not only of manifestations of empowerment, but of the barriers and facilitators that Deaf and disability organizations encounter as they become empowered and seek to increase empowerment in their communities.

**Design and refine culturally sensitive surveys.** Future research could also focus on the design and improvement of culturally sensitive, multi-dimensional surveys of empowerment. Bolton and Brookings (1998), for example, developed a measure of intrapersonal empowerment—a dimension of Zimmerman’s (1995) construct of psychological empowerment—for people with disabilities of unspecified race and ethnicity in the United States, which measured components of personal competence, group orientation, self-determination, and positive disability identity. Even on the individual level of analysis, however, a universal and global measure of empowerment may not be appropriate because it could not account for important differences across people, organizations, and communities (Zimmerman, 1995). Nevertheless, with careful attention, patience, and consultation with Deaf and disabled women from specific communities, researchers could continue designing measures of individual, organizational, and community empowerment, which they could then use to assist in the implementation and evaluation of programs that seek to advance multiple levels of empowerment among Deaf and disabled women.

**Draw from different knowledge traditions.** Finally, future research might also benefit from the exploration of questions of empowerment and identity in relation to or from within various knowledge traditions, such as indigenous knowledges, religious/spiritual approaches, queer theory, and any other epistemological traditions that resonate with participants and co-collaborators of the research. In reviewing some African, Native American, and Eastern psychologies and spiritualities, for example, Ponterotto (2010) described how these historic traditions can provide useful frameworks for considering “the interconnectedness among people, nature, and spirit,” the role of the



self in relation to “communal interdependence,” and the role of humor in wellbeing (p. 742)—frameworks that sound ideal for studying constructs of identity, community, awareness, and social justice. Research involving various religious traditions could explore how they interact with, support (e.g., through philosophies of interdependence), and conflict with (e.g., via the moral model of disability) positive Deaf and disability identities. In addition to the many contributions of feminisms and postcolonial studies, queer theory is particularly well suited for collaborations with Deaf and disability studies. Queer theory not only provides researchers with helpful perspectives for investigating the overlapping injustices experienced by queer and disabled people but also shatters binaries; makes space for nonnormative approaches to sexuality and sex; promotes sexual, reproductive, and parenting rights; and identifies bodies as sites of resistance (e.g., McRuer, 2006). The importance of context and macrosystemic variables in empowerment research demands cross-disciplinary collaborations among wellness professionals, sociologists, economists, political theorists, and so on. In summary, researchers can continue pursuing the transtheoretical, integrative, paradigm-busting, social-justice-oriented approaches of a frenetic social science (e.g., I. Prilleltensky & Nelson, 2009).

### **Implications and Recommendations for Action**

The current study and its applied and theoretical backdrop have a number of implications for policies, programs, activists, and communities. The descriptions of participants’ pursuits of self-advocacy and social justice (Chapters IV and VI) offer a number of specific priorities for action throughout the social ecology. Here, I write more

generally about addressing (a) awareness, (b) barriers, (c) cultures, and (d) distributive justice as focuses for activists and activist organizations.

**Augment awareness.** Participants in the current exploration overwhelmingly emphasized the importance of awareness, and so the first implication for action that I notice is that raising awareness in ourselves, in our organizations, and in the communities we serve seems like a worthwhile endeavor. For example, we can work to give Deaf and disabled women informational access to the laws and policies around health care, domestic violence, and disability rights. At the same time, however, I recommend that we be aware with care—aware of what kinds of knowledges we introduce and spread. We can ask ourselves: How well does this knowledge/perspective draw from or fit with locally grounded perspectives? How likely is it that the information and perspectives that we offer will bring about changes that people in the community want? Failing to consider these questions can threaten or endanger ecosystems and create more barriers for Deaf and disabled women in the communities that we hope to support.

**Break down barriers.** Barriers took up a huge amount of space in participants' empowerment journeys, and thus focusing on eradicating barriers appears to be another important focus for action. Like the participants, we can work to break through barriers in our personal lives and more formally in our activist roles. We can tackle barriers in specific systems, such as families, schools, workplaces, hospitals and medical clinics, law enforcement agencies, activist organizations, and laws and policies at state and international levels. We can address the lack of personal, community, and state resources for accessible housing, personal assistants, sign language interpreters, adaptive devices and technologies, and accessible education. In their activism work, participants

highlighted the mesosystemic relationship between families and schools, facilitating outreach and communication at various stages of Deaf/disability identity development with the purpose of giving Deaf and disabled girls a chance to go to and remain in school. We, too, can make education a priority and facilitate mesosystemic communications. We can try to address attitudinal barriers on a cultural level by conducting psychopolitically valid research, using and critiquing representations of Deafhood and disability in the media, promoting philosophies of interdependence, and increasing the Deaf and disability presence in our communities. We can spread the messages that Deaf and disabled women and girls contribute to the systems around them and are worthy of love, respect, education, economic opportunities, quality health care, protection from violence, and consideration in social action and development projects. I recommend that service providers and activists work all throughout the social ecology and try to increase their focus on meso-, exo-, and macrosystemic levels.

**Concentrate on culture.** Participants shared a few stories about cultural insensitivity among activist organizations, and I certainly have learned more over the course of conducting this dissertation about how complicated and imperative it is to attune to culture. Rather than trying to write general recommendations about cultural attunement, I include here a few example questions to ask when working with Deaf and disabled women, especially in a cross-cultural setting. I might ask myself: To what extent are there Deaf, disabled, and woman-identified employees in my organization who represent the communities we are trying to serve? If we are consulting with Deaf, disabled, or cultural representatives outside the organization, how are we compensating them? How are we continuing to learn about the cultures and communities we serve?

Which spoken, signed, and written languages are we using to spread information? If we are working with sign language interpreters, what genders and cultures do they represent? To what extent are Deaf participants comfortable with their interpreters—e.g., how do interpreters’ genders and cultural backgrounds meet the cultural needs (power-with vs power-over) of participants. Are we working with certified Deaf interpreters in addition to hearing interpreters? Do we have written information available in braille and accessible electronic formats? How are we delivering programs, services, and information to members of the community? Are our program activities and settings physically accessible to program participants? To what extent do we factor breaks and rest into our program activities? How are we seeking feedback from participants and evaluating our programs? These questions and others like them might help mitigate unintended paternalistic or colonizing effects, ensure that programs are culturally congruent, and maximize positive impact.

**Defend distributive justice.** Raising awareness, eradicating barriers, and attuning to cultures and contexts are not enough; the systems and structures need to change from local to global levels. I. Prilleltensky and Nelson (2009) defined distributive justice as “the fair and equitable allocation of bargaining power, resources, and burdens in society” (p. 134). The stories of 21 Deaf/disabled women activists in the current study offer a small but compelling example of the unfair and imbalanced distribution of bargaining power, resources, and burdens across the world. Individual advocates and activist organizations cannot address barriers on a case by case basis indefinitely. I would also argue that the cost is too high—in terms of safety, health, poverty, education, social

participation, etc.—to wait for seeds of change to take root in the existing, often inhospitable context.

One way to radically redistribute is to practice and encourage depowerment. Depowerment is “the process whereby people who are privileged share power with people who are disadvantaged” (I. Prilleltensky & Nelson, 2009, p. 142). Participants practiced depowerment by passing up and passing along opportunities to other Deaf or disabled women. But how can activists go about convincing the overpowered to pass along or redistribute their power? As I think back to my impatience with metaphors of winning and losing (refer to Chapter II), I wonder if scholars and activists might change the discourse from reflecting a power-over, power scarcity mentality to reflect more of an interdependence, power-sharing mindset. Ultimately, I believe that it benefits all of the human and non-human world to decrease disparities because I recognize that we are interdependent and interconnected. As an activist, one of my projects is to live this *conocimiento* (Anzaldúa, 2015) and share it as best I can.

**To what extent can we empower others?** A discussion of implications and recommendations for action would not be complete without a return to the paradox of helping and the paradox of empowerment. When activists strive to raise awareness, remove barriers, attune to culture, and redistribute material and social resources, are they empowering Deaf and disabled women? My flippant answer is: It depends, as do we all. Our ability to empower others depends, I believe, on how successful we are at sharing power rather than prescribing our own norms, at heeding the guidance of Deaf and disabled women, and at changing the oppressive systems and structures and the wider contexts in which we/they live. “We do not do empowerment to others or bestow it upon

them; empowerment happens with others, within a context, and we shape that context as do those with whom we work” (McWhirter, 1994, p. 2).

### **Conclusion: The Empowerment Metaphor**

The results of the current exploration suggest that empowerment is, in many respects, a journey traveled by Deaf and disabled women activists (refer to Chapter V). This journey involves orienting to twinkling constellations of values, desires, hopes and dreams and using them to guide navigation and travel. It involves exploring landscapes of self, identity, and spirit, as well as multiple spheres of the social ecology. Although barriers can be some of the most prominent features in a rugged terrain, the traveler devises some strategies for staying oriented, strengthening her vehicle, changing her inner and outer landscapes, and traveling with valued companions. Her relationships and social networks can provide, not just companionship, but extra fuel for the journey, a boost over a particular barrier, or extra strength in numbers.

The journey metaphor is not enough to illuminate and elaborate the many processes and outcomes of empowerment in the current exploration, however. More than just a journey, empowerment is knowledge, access, freedom, interconnectedness—a positive identity intertwined with affirming communities. Empowerment involves processes of growing and flourishing, leaning into tensions, dancing amid contradictions, learning, teaching, working hard, playing, allowing, adapting, resisting, and creating.

Perhaps most importantly, the results of this research illustrate how empowerment must transcend individuals and manifest in the environment. Empowerment is a loving family, communication in sign language, a cartoon about educating girls, enough money to go to school or run an organization, an inclusive classroom, a braille book, teachers

and interpreters who sign, a ramp, a rollator, a wheelchair, a crutch, a white cane, an affirming workplace, a safe walk/roll home from work, the opportunity to travel abroad, a community dance party, and a news station willing to change the language that its journalists use to discuss disability. Empowerment exists and, indeed, depends on every system of the social ecology. In this respect, empowerment is a biodiverse and changing garden, as well as all the global conditions under which such gardens can thrive.

## APPENDIX A

### RECRUITMENT LETTER IN ENGLISH



UNIVERSITY OF OREGON

#### English Recruitment Letter for Pre-departure Packets

Dear WILD participant,

My name is Audrey Medina, and I am a blind student in the counseling psychology department at the University of Oregon. I am writing to invite you to participate in my dissertation research, which is about how women with disabilities from many different backgrounds increase their leadership strength as individuals and as part of social groups. I would love to include you in this study because you are a WILD woman with a disability who demonstrates individual and cooperative strength through your leadership.

If you decide to participate in this study, I will ask you (1) to join me in a one-hour interview during your stay in Eugene, Oregon, (2) to hold a 20-30 minute conversation with me over Skype or on the phone when you first return home, and (3) to participate in another one hour interview with me over Skype, on the phone, or in person three to seven months after the WILD program ends. I will ask your permission to audio record our interviews so that I can refer back to them as part of my research. During the WILD program, I plan to participate as a volunteer and observer, so we will have many opportunities to get to know one another.

Your participation in my study is completely voluntary. You can choose to be in the study or not, and you can change your mind at any time. I will introduce myself in person once you arrive in Eugene, and we can talk more about my research at that time. If you have any questions about the study before you arrive, please feel free to contact me at [medina@uoregon.edu](mailto:medina@uoregon.edu). Thank you very much, and I look forward to meeting you soon!

Sincerely,

Audrey

Medina , English Recruitment Letter for Pre-departure Packets 7/1/2013



## RECRUITMENT LETTER IN SPANISH



UNIVERSITY OF OREGON

### **Español Carta de Solicitación para Paquetes de Pre-Partida**

Querido Participante WILD,

Mi nombre es Audrey Medina, y yo soy una estudiante ciega en el departamento de asesoría psicológica en la Universidad de Oregón. Yo estoy escribiendo para invitar su participación en mi investigación, cuya investigación trata entender cómo es que las mujeres con discapacidades de diferentes historiales aumentan la fortaleza de su liderazgo como individuos y como parte de grupos sociales. Me encantaría incluirle en este estudio porque usted es una mujer WILD con una discapacidad quien ha demostrado fortaleza individual y cooperativa a través de su liderazgo.

Si decides participar en este estudio, yo la preguntaré (1) que participas en una entrevista de una hora mientras que estas hospedada en Eugene, Oregón (2) tener una conversación conmigo por medio de Skype o por teléfono después de que regresas a su hogar, y (3) participar en otra entrevista de una hora y media por Skype, o por teléfono, o hablaremos en persona, tres a siete meses después que termine el programa WILD. Pediré su permiso hacer una grabación en audio de nuestras entrevistas para que pueda analizarlas como parte de mi investigación. Durante el programa WILD, yo participaré como una voluntaria, así es que tendremos muchas oportunidades para conocernos una a la otra.

Su participación en mi estudio es completamente voluntaria. Usted puede escoger si quiere participar o no, hasta puedes cambiar de idea a cualquier momento si te decides ya. Yo me presentaré en persona cuando llegue usted a Eugene, y podemos hablar más sobre mi investigación en ese tiempo. Si tienes preguntas sobre el estudio antes de su llegada, no se detenga de contactarme al [medina@uoregon.edu](mailto:medina@uoregon.edu). ¡Muchísimas gracias y espero conocerte mejor!

Muy atentamente,

Audrey

Medina , Spanish Recruitment Letter for Pre-departure Packets 7/1/2013

## APPENDIX B

### INFORMED CONSENT DOCUMENT IN ENGLISH



UNIVERSITY OF OREGON

**University of Oregon Department of Counseling Psychology**  
**Informed Consent for Participation as a Subject in**  
**“WILD Leaders: An exploration of empowerment and identity salience among**  
**women with disabilities from around the world”**

**Investigator: T. Audrey Medina**

**Type of consent: Participant Consent Form**

#### **Introduction**

- I would like to invite you to be in a research study. I am interested in the experiences of women with disabilities from many different backgrounds and how they increase their strength as individuals and as part of social groups.
- I would like to work with you because you are a woman with a disability who demonstrates strength through your leadership.
- Please read this form and ask any questions that you might have before you agree to be in the study.

#### **Purpose of Study:**

- The purposes of this study are to learn (1) more about what women like you experience as you become leaders, (2) how different parts of who you are, such as your age, gender, religion, disability, and/or national origin, play a role in your experiences, (3) what experiences you have during the WILD program, and (4) how you sustain your leadership strength once you return home.
- All 22 WILD women are welcome to participate in this study. Participants will have a range of disabilities, come from many different countries, and have a variety of other backgrounds.

#### **Description of the Study Procedures:**

- If you agree to be in this study, I will ask you (1) to participate in a one-hour interview with me during the WILD program, (2) to have a 20-30 minute conversation with me over Skype or on the phone when you first return home, and (3) to participate in a one-hour interview with me over Skype, on the phone, or in person three to seven months after the WILD program ends. I will spend time with you during WILD and observe the WILD activities. I would also like your permission to access your WILD application to learn more about your background, such as your age, country of origin, and leadership work.

#### **Risks/Discomforts of Being in the Study:**

- I do not think that my study will pose many risks. That said, there are two possible risks that I would like to mention.
- First, our interviews might touch upon emotional and personal topics as you share the story of how you became a leader. You will, however, always have the choice not to answer the questions that I ask.
- Second, even though I will do my best to protect your identity if you choose, there is always the possibility that someone may recognize a part of your story when I report the results of my research.
- Please ask me any questions that you have about these risks, and let me know of any other risks that may apply to you in particular. We will work together to minimize them.

#### **Benefits of Being in the Study:**

- The purpose of this study is to offer women with disabilities an opportunity to share their experiences with the world and to help us all learn more about how to increase our individual and cooperative strength.
- I believe that the act of telling our stories may be a beneficial experience in itself.
- The stories of WILD women can also help (1) inform theories about empowerment and identity, which can advance work in human services and human rights, (2) enrich the understandings of people with and without disabilities, and (3) provide useful information to MIUSA and the WILD program.

#### **Payments:**

- There will be no payment for participation in this study, though I offer you much gratitude.

#### **Costs:**

- There is no financial cost to you for participating in this research study.

#### **Confidentiality:**

- The records of this study will be kept private. In any report that I might publish, I will not include any information that will make it possible to identify you if you would like to have your identity protected. I will keep research records in a locked file, and I will secure all electronic information by using codes instead of your name and by using passwords to protect the files.
- After each of our three interviews, I will ask you what level of confidentiality you would prefer: You may choose from the following options:
  - a) full confidentiality, which involves protecting and disguising your identity as much as possible,
  - b) Partial confidentiality, which involves using a pseudonym that would likely reveal your identity only to MIUSA and to other people who know you);
  - c) full identification, which involves using your real name in relation to the story that you share during our interviews.
- You can change your mind about your confidentiality preference at any time over the course of this research project (that is, within the next year).
- I have hired a transcriptionist who will help transcribe the recordings of our interviews into text; she has signed a confidentiality agreement and may not disclose any

information that she hears from our interviews. My academic advisor, research assistants, and the translators/interpreters who will help during the interviews have also signed confidentiality agreements and are not permitted to speak about the content of our conversations.

- Access to study records will be limited to my research team; however, please note that the Institutional Review Board and internal University of Oregon auditors may review the research records to ensure that I am adhering to ethical standards.

**Voluntary Participation/Withdrawal:**

- Your participation is voluntary. If you choose not to participate, your choice will not have a negative effect on your current or future relationship with the University of Oregon, with MIUSA, or with me.
- You are free to withdraw at any time for any reason.

**Contacts and Questions:**

- I, Audrey Medina, am the researcher conducting this study. If you have questions or concerns, or if you would like more information about this research, you may contact me at [medina@uoregon.edu](mailto:medina@uoregon.edu) or 1-707-706-3824; my Skype name is tmedina12. You may also contact my academic advisor, Dr. Krista Chronister, at [kmg@uoregon.edu](mailto:kmg@uoregon.edu) or 541-346-2415.
- If you have any questions about your rights as a research participant, you may contact: Research Compliance Services, University of Oregon at [ResearchCompliance@uoregon.edu](mailto:ResearchCompliance@uoregon.edu) or (541) 346-2510.

**Copy of Consent Form:**

- You will be given a copy of this form to keep for your records and future reference.

**Your Statement of Consent:**

- I have read or have had read to me the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this study. I have received (or will receive) a copy of this form.

**Study Participant (Print Name)**

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**Study Participant Signature**

**Date**

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**Statement of Consent for Audio recording of Interviews:**

- I give permission to have my voice recorded during the interviews for this study.

**Study Participant Signature**

**Date**

## INFORMED CONSENT DOCUMENT IN SPANISH



UNIVERSITY OF OREGON

**Universidad de Oregon Departamento de Asesoría Psicológico**  
**Consentimiento Informado para Participar como Sujeto en**  
**“WILD Líderes: Una exploración de empoderamiento y rasgos sobresalientes**  
**de identidad entre mujeres con discapacidades en el mundo”**

**Investigador: T. Audrey Medina**

**Tipo de consentimiento: Impreso de Consentimiento del Participante**

### **Introducción**

- Yo quisiera invitarla a participar en este estudio de investigación. Estoy interesada en las experiencias de mujeres con discapacidades de diferentes antecedentes e historiales, como aumentan la fuerza como individuos e igual como parte de un grupo social.
- Yo quisiera trabajar con usted porque eres una mujer discapacitada que muestra fortaleza por medio de su liderazgo.
- Por favor lea este impreso y haz cualquier pregunta que tengas antes que aceptas participar en este estudio.

### **Propósito del Estudio:**

- El propósito de este estudio es conocer (1) más sobre las experiencias que mujeres como usted enfrentan al convertirse en líderes, (2) como las varias partes de quien eres, su edad, género, religión, discapacidad, origen nacional, impactan sus experiencias, (3) que experiencias tienes mientras participas en el programa WILD, y (4) como mantienes la fortaleza de tu liderazgo cuando regresas a su hogar.
- Todas las 25 mujeres del programa WILD están invitadas a participar en este estudio. Los participantes tendrán una gama de discapacidades, tal como son de diferentes países, y una variedad de historiales.

### **Descripción de los Procedimientos del Estudio:**

- Si decides participar en este estudio, yo preguntaré (1) que participas conmigo en una entrevista de una hora durante el tiempo que asistas al programa WILD, (2) tener una conversación de 20 a 30 minutos por Skype o por teléfono conmigo cuando apenas regresas a su hogar, y (3) participar en un entrevista de una hora por Skype, por teléfono, o en persona conmigo al pasar tres a siete meses después de que termina las actividades del programa WILD. Quisiera también tener su permiso revisar su aplicación del programa WILD para conocer más sobre sus antecedentes, como su edad, país de origen, y tipo de trabajo.

### **Riesgos/Disconformidades de Participar en el Estudio:**

- Yo no pienso que mi estudio no presentará muchos riesgos. Sin embargo, existen dos posibles riesgos que quiero mencionar.
- Primeramente, nuestra entrevista podrá abrir temas personales y emocionantes mientras que usted comparta su historia de cómo llegaste a ser líder. Tendrás siempre, por lo tanto, la opción de no contestar las preguntas que yo hago.

- Segundo, aunque yo haré todo lo posible para proteger su identidad, si lo deseas, siempre existe la posibilidad que alguien reconozca una parte de su historial cuando yo hago mi reporte sobre la investigación.
- Finalmente, tenga la confianza de hacerme preguntas sobre estos riesgos. Igual, tenga la bondad de informarme de riesgos que aplicarán en particular a su situación, y juntas trabajaremos para minimizarlos.

#### **Beneficios de Participar en el Estudio:**

- El propósito de este estudio es ofrecer a mujeres con discapacidades una oportunidad para compartir sus experiencias con el mundo y ayudar a todos nosotros aprender cómo aumentar nuestra fortaleza individual y cooperativa.
- Yo creo que el hecho de compartir nuestros historiales puede ser una experiencia beneficiosa en sí.
- Los historiales de mujeres WILD pueden también ayudar (1) a informar sobre teorías de empoderamiento e identidad, las cuales pueden avanzar el trabajo de servicios humanos y derechos humanos, (2) enriquecer el entendimiento de personas con o sin discapacidades, y (3) brindar información útil a MIUSA y el programa WILD.

#### **Pagos:**

- No habrá pago por participar en este estudio, pero les ofrezco mucha gratitud.

#### **Gastos:**

- No hay ningún gasto por su participación en este estudio investigativo.

#### **Confidencialidad:**

- Los datos de este estudio se mantendrán privados. En cualquier reporte que se publicara, yo no incluiré cualquier tipo de información que haga posible identificarla si usted quiere que su identidad sea protegida. Yo mantendré los datos investigativos en una vitrina con candado, y yo aseguraré toda la información electrónica por medio de códigos en vez de los nombres y a través de contraseñas para proteger los archivos.
- Después de nuestras tres entrevistas, yo pediré que nivel de confidencialidad quiere: usted puede escoger una de las siguientes tres opciones:
  - a) confidencialidad completa, que involucra proteger y disfrazando su identidad lo más posible,
  - b) confidencialidad parcial, que involucra el uso de seudónimos que posiblemente revelara su identidad a MIUSA y a otras personas que conoce,
  - c) identificación total, que involucra el uso de su nombre real en relación con su historial que compartas durante nuestras entrevistas.
- Usted puede cambiar de idea sobre su preferencia de confidencialidad a cualquier momento sobre la trayectoria de este proyecto investigativo (es decir, durante el siguiente año).
- Yo he contratado una transcripcionista quien ayudara transcribir en texto las grabaciones de nuestras entrevistas; ella ha firmado un acuerdo de confidencialidad y no podrá divulgar cualquier información que ella oye en las grabaciones de nuestras entrevistas. Mi asesor académico, asistente investigativo, y los traductores e intérpretes quienes ayudaran durante las entrevistas también han firmado acuerdos de confidencialidad y no serán permitidos hablar sobre el contenido de nuestras conversaciones.

- Acceso a los datos de este estudio serán limitadas a la vista del conjunto investigativo; sin embargo, por favor nota que el Cuerpo Interno de Supervisión y auditores internos de la Universidad de Oregon podrán revisar los datos investigativos oficiales para asegurar que yo estoy adhiriendo a las normas éticas.

**Participacion y exclusión voluntario:**

- Su participación es voluntario. Si decides no participar, su decisión no tendrá un efecto negativo en tu relación futura con la Universidad de Oregon, con MIUSA, o conmigo.
- Tienes la libertad de retirar de participación por cualquier razón.

**Contacto y Preguntas:**

- Yo, Audrey Medina, soy el investigador conduciendo este estudio. Si tienes preguntas o preocupaciones, o si quieres más información sobre esta investigación, puedes contactarme por [medina@uoregon.edu](mailto:medina@uoregon.edu). También puedes contactar mi asesor académico, la Doctora Krista Chronister, por [kmg@uoregon.edu](mailto:kmg@uoregon.edu) o al 541-346-2415.
- Si tienes preguntas sobre sus derechos como participante de investigación, puedes contactar:

Research Compliance Services, University of Oregon at  
[ResearchCompliance@uoregon.edu](mailto:ResearchCompliance@uoregon.edu) o al 541-346-2510.

**Copia del Impreso de Consentimiento:**

- Recibirás una copia de este impreso para sus archivos y futura referencia.

**Su Declaración de Consentimiento:**

- Yo he leído o me han leído el contenido de este impreso de consentimiento y me han animado hacer preguntas. He recibido respuesta a mis preguntas. Yo doy mi consentimiento de participación en este estudio. He recibido (o recibiré) una copia de este impreso.

**Participante del Estudio (Deletrea su Nombre)**

---

**Firma del Participante** **Fecha**

---

**Declaracion de consentimiento para una Grabacion en Audio de las Entrevistas:**

- Yo doy permiso que graben mi voz durante las entrevistas para este estudio.

**Firma del Participante** **Fecha**

---

## APPENDIX C

### CONFIDENTIALITY AGREEMENT FOR TRANSLATORS, INTERPRETERS, TRANSCRIPTIONISTS, AND RESEARCH ASSISTANTS



UNIVERSITY OF OREGON

#### Confidentiality Agreement for Translators, Interpreters, Transcriptionists, and Research Assistants

**Principal Investigator:** Audrey Medina<sup>[1]</sup><sub>SEP</sub> **Department:** Counseling Psychology, University of Oregon

**Project Title:** “WILD leaders: An exploration of empowerment and identity salience among women with disabilities from around the world”

I understand that, as a translator/interpreter/transcriber working with Audrey Medina on research-related interviews, I am required to maintain and protect the confidentiality of the information divulged by participants of the interviews that we conduct and record. I agree not to disclose the information gathered during the interviews to anyone other than the principal investigator. I agree also not to disclose the identities and information about the identities of individuals who participate in the interviews.

My signature confirms that I will abide by this agreement and that I will preserve the confidentiality of all proceedings, information gathered and transcribed, and identities of participants in the interviews.

---

**Signature**

---

**Date**



## APPENDIX D

### INFORMAL OUTLINE FOR INITIAL INTERVIEW

Thank you so much for having a conversation with me today! I am looking forward to learning more about you and about how you became a leader as a woman with a disability. I think our interview will last about an hour, and I am recording our voices. If, at any point, I ask you a question that you do not want to answer, please tell me. The purpose of my research is to learn more about the rich stories of women with disabilities, so this interview is about you and what you would like to share.

Okay, as you already know, I am interested in two main topics. First, I am interested in how women with disabilities from around the world become leaders—how they develop inner strength, take action, work with others, etc. Second, I am interested in the many parts of people's identities—what it means to them to be a woman with a disability, of a certain ethnicity or nationality, of a certain age or religion, whatever is important to them. Do you have any questions before we begin?

#### Questions and Possible Prompts

- Would you tell me a little bit about why you applied for the WILD program?
  - What did you hope to gain from attending WILD?
  - How would that knowledge/skill/confidence help you in your life?
- Would you tell me the story of how you became the leader that you are today?
  - What are some of the experiences that led you to being here today, participating in WILD?
- Would you tell me about your experiences as a woman, a woman with with a disability in your community/country?
  - What else should I know about who you are? Your age, religion, ethnicity?
  - How are those identities important to you?
- What kinds of challenges and barriers have you encountered as you work at being a leader? (To what extent do you relate to the term leader?)
  - Did you encounter similar challenges/barriers in your school/family/work/community?
  - Do you still encounter these challenges/barriers?
- How did you deal with the challenges/barriers that you encountered?
  - How did you work with other people in your family/school/work/community?
  - What kinds of decisions did you have to make?
  - What kinds of actions did you take?
  - What did you think or do to help you build inner strength?
  - Is there a song or picture that you find particularly inspiring?
- Before we end, I'd like to ask you about your confidentiality preference for this interview. Would you like me to fully disguise your identity, partially disguise your identity by using a pseudonym, which would probably identify you to MIUSA and other people who know you, or use your real name in relation to your story?
  - What would you like your pseudonym to be?

Thank you for talking with me! As always, please feel free to be in touch with any additional thoughts or questions that you have. As soon as I can, I will send you the transcript for this interview for you to enjoy and comment on if you like.

## APPENDIX E

### INFORMAL OUTLINE FOR FOLLOW-UP INTERVIEW

Thank you so much for talking with me again! This interview will last about an hour, and I am recording our voices. I'm hoping to follow up on some things that we talked about in our last conversation, to learn more about how you experienced the WILD program, and to find out how you are doing now that you have been home for a while. As before, if I ask a question that you do not feel comfortable answering, just let me know. Do you have any questions before we begin?

#### Questions and Possible Prompts

- Most importantly, how are you doing?
  - When we last talked, you said you were feeling...How are you feeling now that you have been back in your family/school/work/community for a few months?
- What was your experience like in the WILD program?
  - Would you tell me a story that stands out to you from your time during the program?
- What was it like being a woman with a disability in the WILD program [also include other identities that we discussed before]?
- How are you thinking about your identity now that you're home?
- What did you learn about being a leader in the WILD program?
  - What kind of knowledge, perspectives, or skills did you develop at WILD?
- What is it like for you being a woman leader with a disability now that you are home?
- What is going well?
- What challenges or barriers have you encountered since returning home?
  - Last time, you mentioned your (e.g., family, work, physical access around town). How are things going in those environments?
- How are you addressing these challenges/barriers?
  - What actions do you take?
  - What do you think or do to keep up your inner strength?
  - How do you work with others to address challenges/barriers?
- What else is important for me to know about either your experience during WILD or about your return home?
- Before we end, I'd like to ask you about your confidentiality preference for this interview. Would you like me to fully disguise your identity, partially disguise your identity by using a pseudonym, which would probably identify you to MIUSA and other people who know you, or use your real name in relation to your story?
  - What would you like your pseudonym to be?

Thank you very much for your time. As always, please feel free to be in touch with any additional thoughts or questions that you have. As soon as I can, I will send you the

transcript of this interview for you to enjoy and comment on if you like. It has been lovely talking with you and getting to know you over the past months. Be well.

## APPENDIX F

### INFORMED CONSENT FOR HOME VISITS



UNIVERSITY OF OREGON

**University of Oregon Department of Counseling Psychology**  
**Informed Consent for Participation as a Subject in**  
**“WILD Empowerment: An exploration of empowerment and identity salience among**  
**women with disabilities from around the world”**

**Investigator: T. Audrey Medina**

**Type of consent: Participant Consent Form**

#### **Introduction**

- I would like to invite you to continue in my research study. I am interested in the experiences of women with disabilities from many different backgrounds and how they increase their strength as individuals and as part of social groups.
- I would like to work with you because you are a woman with a disability who demonstrates strength through your work.
- Please read this form and ask any questions that you might have before you agree to be in the study.

#### **Purpose of Study:**

- The purposes of this study are to learn (1) more about what women like you experience as you become leaders, (2) how different parts of who you are, such as your age, gender, religion, disability, and/or national origin, play a role in your experiences, (3) what experiences you have during the WILD program, and (4) how you sustain a sense of empowerment once you return home.
- All 21 WILD women are welcome to participate in this study, though I will only be able to visit two or three in their home countries. Participants will have a range of disabilities, come from many different countries, and have a variety of other backgrounds.

#### **Description of the Study Procedures:**

- If you agree to continue in this study, I will ask you (1) to participate in a one-hour follow-up interview with me in your home country and (2) to allow me to observe some aspects of your work, home, and community life. You can choose what you would like me to observe. I also plan to conduct independent research about the history and culture of your country and would be happy to investigate any resources that you would like to recommend.

#### **Risks/Discomforts of Being in the Study:**

- I do not think that my study will pose many risks. That said, there are two possible risks that I would like to mention.

- First, our interviews might touch upon emotional and personal topics as you share the story of how you became a leader. You will, however, always have the choice not to answer the questions that I ask.
- Second, even though I will do my best to protect your identity if you choose, there is always the possibility that someone may recognize a part of your story when I report the results of my research.
- Please ask me any questions that you have about these risks, and let me know of any other risks that may apply to you in particular. We will work together to minimize them.

#### **Benefits of Being in the Study:**

- The purpose of this study is to offer women with disabilities an opportunity to share their experiences with the world and to help us all learn more about how to increase our individual and cooperative strength.
- I believe that the act of telling our stories may be a beneficial experience in itself.
- By visiting your country, I hope to increase my understanding about the environments in which you live and work.
- The stories of WILD women can also help (1) inform theories about empowerment and identity, which can advance work in human services and human rights, (2) enrich the understandings of people with and without disabilities, and (3) provide useful information to MIUSA and the WILD program.

#### **Payments:**

- There will be no payment for participation in this study, though I offer you much gratitude.

#### **Costs:**

- There is no financial cost to you for participating in this research study.

#### **Confidentiality:**

- The records of this study will be kept private. In any report that I might publish, I will not include any information that will make it possible to identify you if you would like to have your identity protected. I will keep research records in a locked file, and I will secure all electronic information by using codes instead of your name and by using passwords to protect the files.
- After each of our three interviews, I will ask you what level of confidentiality you would prefer. Please choose one of the following options:
  - a) full confidentiality, which involves protecting and disguising your identity as much as possible,
  - b) Partial confidentiality, which involves using a pseudonym that would likely reveal your identity only to MIUSA and to other people who know you);
  - c) full identification, which involves using your real name in relation to the story that you share during our interviews.
- You can change your mind about your confidentiality preference at any time over the course of this research project (that is, within the next six months).
- I have hired a transcriptionist who will help transcribe the recordings of our interviews into text; she has signed a confidentiality agreement and may not disclose any

information that she hears from our interviews. My academic advisor, research assistants, and the translators/interpreters who will help during the interviews have also signed confidentiality agreements and are not permitted to speak about the content of our conversations.

- Access to study records will be limited to my research team; however, please note that the Institutional Review Board and internal University of Oregon auditors may review the research records to ensure that I am adhering to ethical standards.

**Voluntary Participation/Withdrawal:**

- Your participation is voluntary. If you choose not to participate, your choice will not have a negative effect on your current or future relationship with the University of Oregon, with MIUSA, or with me.
- You are free to withdraw at any time for any reason.

**Contacts and Questions:**

- I, Audrey Medina, am the researcher conducting this study. If you have questions or concerns, or if you would like more information about this research, you may contact me at [medina@uoregon.edu](mailto:medina@uoregon.edu) or 1-707-706-3824; my Skype name is tmedina12. You may also contact my academic advisor, Dr. Krista Chronister, at [kmg@uoregon.edu](mailto:kmg@uoregon.edu) or 1-541-346-2415.
- If you have any questions about your rights as a research participant, you may contact: Research Compliance Services, University of Oregon at [ResearchCompliance@uoregon.edu](mailto:ResearchCompliance@uoregon.edu) or 1-541-346-2510.

**Copy of Consent Form:**

- You will be given a copy of this form to keep for your records and future reference.

**Confidentiality:**

- The records of this study will be kept private. In any report that I might publish, I will not include any information that will make it possible to identify you if you would like to have your identity protected. I will keep research records in a locked file, and I will secure all electronic information by using codes instead of your name and by using passwords to protect the files.
- After each of our three interviews, I will ask you what level of confidentiality you would prefer. Please choose one of the following options:
  - Full confidentiality, which involves protecting and disguising your identity as much as possible,
  - Partial confidentiality, which involves using a pseudonym that would likely reveal your identity only to MIUSA and to other people who know you);
  - Full identification, which involves using your real name in relation to the story that you share during our interviews.
- You can change your mind about your confidentiality preference at any time over the course of this research project (that is, within the next six months).
- I have hired a transcriptionist who will help transcribe the recordings of our interviews into text; she has signed a confidentiality agreement and may not disclose any information that she hears from our interviews. My academic advisor, research assistants, and the translators/interpreters who will help during the interviews have also

signed confidentiality agreements and are not permitted to speak about the content of our conversations.

- Access to study records will be limited to my research team; however, please note that the Institutional Review Board and internal University of Oregon auditors may review the research records to ensure that I am adhering to ethical standards

Your Statement of Consent:

- I have read or have had read to me the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this study. I have received a copy of this form.

**Study Participant (Print Name)**

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**Study Participant Signature**

**Date**

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**Statement of Consent for Audio recording of Interviews:**

- I give permission to have my voice recorded during the interviews for this study.

**Study Participant Signature**

**Date**

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## APPENDIX G

### CONTENT CODES

*The Content Categories and Codes that Emerged from Grounded Theory Analyses*

Awareness of self	Awareness of context and power	Barriers	Supports	Activism	Personal strategies	Personal impact
Acknowledging own strengths and power	Demonstrating awareness of environment	Encountering ableism or audism	Being encouraged by others	Advocating	Challenging self	Doubting self
Acknowledging privilege	Deploing a charity model	Encountering access, communication or information barriers	Being made aware by others	Building community or professional network	Concealing personal impact	Experiencing loss
Describing transformation	Describing ableism or audism	Encountering colonialism, racism, tribalism	Being recognized or appreciated	Changing attitudes-expectations	Developing confidence	Experiencing pain, exhaustion, and stress
Discussing 'normal' identity	Describing access, communication and information barriers	Encountering corruption	Benefitting from education or training	Collaborating and cooperating	Discerning intentions	Feeling alone, misunderstood

APPENDIX G CONTENT CODES (continued).

Awareness of self	Awareness of context and power	Barriers	Supports	Activism	Personal strategies	Personal impact
Discussing deaf and disability identity	Describing colonialism, racism, tribalism	Encountering resistance, conflict or criticism	Experiencing access	Developing or coordinating programs	Embracing opportunities and experiences	Feeling angry, frustrated
Discussing educated identity	Describing conflict, restrictions or lack of autonomy	Encountering sexism or gender oppression	Experiencing advocacy on her behalf	Educating and training PWDs	Engaging with the arts	Feeling anxious or afraid
Discussing identity within family	Describing corruption	Experiencing bodily realities	Experiencing love, acceptance, and support	Educating the public	Experiencing success	Feeling gratitude
Discussing national cultural identity	Describing financial barriers	Experiencing physical and sexual violence	Having role models	Encouraging or motivating others	Expressing herself	Feeling happy, hopeful
Discussing other aspects of identity	Describing gradual progress	Experiencing rejection or exclusion	Having Sovereignty Supported	Engaging in the political systems	Finding meaning or purpose	Feeling hurt by others

APPENDIX G CONTENT CODES (continued).

Awareness of self	Awareness of context and power	Barriers	Supports	Activism	Personal strategies	Personal impact
Discussing professional identity and role	Describing physical or sexual violence	Experiencing religious intolerance	Receiving financial support and resources	Holding leadership positions	Getting along, fitting in	Feeling love and compassion
Discussing religious or spiritual identity	Describing sexism or gender oppression	Experiencing restrictions or lack of autonomy	Receiving opportunity	Raising funds or giving personal donations	Getting fed up	Feeling motivated
Discussing woman identity	Describing skill deficits	Lacking awareness	Receiving specific help	Representing the group	Having faith	Feeling proud
Expanding self knowledge	Describing specific PWDs	Lacking opportunities	Using technology or tools	Researching, gathering information	Laughing, using humor	Feeling sad, discouraged, uninspired
Having a drive to learn	Endorsing a rights-based model	Lacking resources, encountering financial barriers		Resisting injustice	Making comparison	Feeling surprised
Having desires, hopes and dreams	Expanding awareness of environment	Lacking skills		Sharing stories	Making connections and finding community	Feeling validated

APPENDIX G CONTENT CODES (continued).

Awareness of self	Awareness of context and power	Barriers	Supports	Activism	Personal strategies	Personal impact
Identifying age	Perpetuating stereotypes	Lacking supportive relationships		Using media	Making decisions	Recognizing consequences of Hard Decisions
Identifying as different, non conformer	Recognizing importance of education and awareness			Volunteering	Orienting to values	
Identifying with sports	Recognizing importance of stories				Persevering	
					Planning, preparing	
					Practicing acceptance	
					Practicing self care	
					Practicing spirituality	

APPENDIX G CONTENT CODES (continued).

Awareness of self	Awareness of context and power	Barriers	Supports	Activism	Personal strategies	Personal impact
					Pursuing education or learning	
					Pursuing Sovereignty	
					Seeking employment	
					Traveling	
					Using creative problem solving	
					Working extra hard	

## APPENDIX H

### CONTEXT CODES

*The Context Categories and Codes that Emerged from Grounded Theory Analyses*

Ecological context	Background topics
Activist organizations	Access inclusion
Couple's relationships	Civil and human rights
Deaf and disability community	Communication, cooperation, connectedness
Family	Education and learning
Government law and politics	Employment
History	Empowerment and strength
Hospital or other institution	Funding and other resources
Individual	General deaf, disability and WWD issues
Local community	Health and wellness
Mentorship relationship	Identity
National context	Legal issues and compliance
Peer relationships	Organizational logistics
Physical environment and infrastructure	Parenting and Families
Religious community	Personal authority
School education context	Relationships
Socio cultural environment	Technology
Transnational context	Transportation

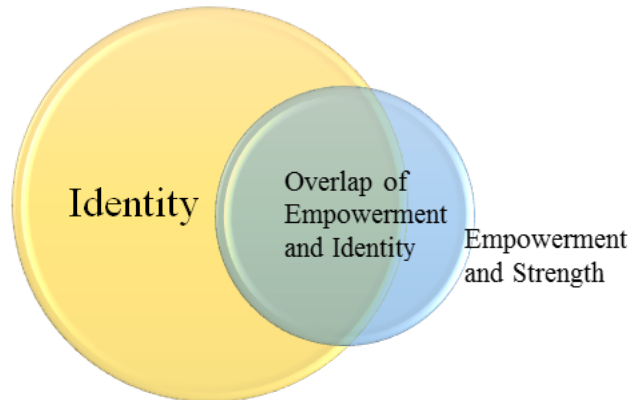
APPENDIX H CONTEXT CODES (continued).

Ecological context	Background topics
WILD program	Violence
Work place	Women and girls
	Youth

## Appendix I

### VENN DIAGRAM: OVERLAP OF EMPOWERMENT AND IDENTITY

This venn-diagram is a visual representation of the amount of participants' interview transcripts that I coded as related to identity (the yellow circle) and as related to empowerment (the blue circle). The green overlapping region represents the amount of text coded as both identity and empowerment.





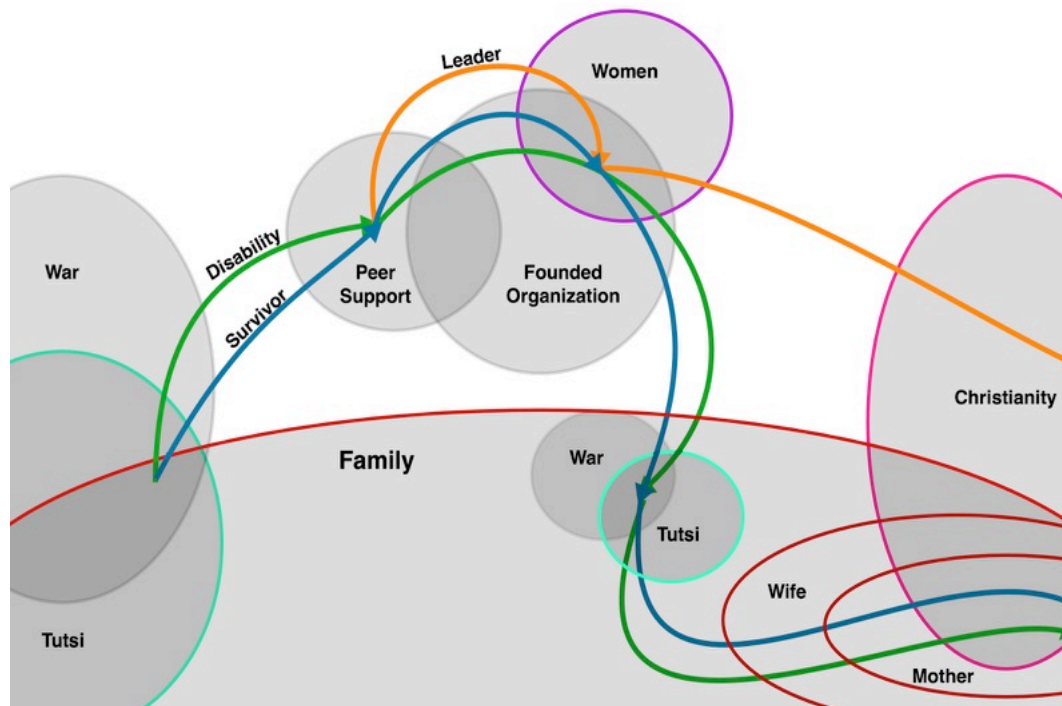
## WORD CLOUD DIAGRAM: DESIRES, HOPES, AND DREAMS



## APPENDIX K

### CHARITY IDENTITY MAP: ILLUSTRATES CHARITY'S SALIENT, INTERSECTING IDENTITIES AS SHARED IN HER STORY

Living through genocide as a Tutsi and losing much of her family generated Charity's IDs as a survivor and woman with a psychosocial disability. When Charity found a community of people with psychosocial disabilities after the war, her survivor and disability IDs intersected and generated a leadership ID. As she helped found an activist organization, her survivor, disability, and woman IDs intersected and helped organize her leadership ID. Her Christian ID also helped organize her leader ID. At the time of our interviews, Charity's IDs as a Tutsi, survivor, woman with psychosocial disability, wife, mother, and Christian wove in and out of one another in complicated ways.



Note. In these identity maps, the colored lines represent identities and how they moved and interacted with each other in a snapshot of a participant's identity story. The shaded ovals symbolize experiences or ecological contexts that influenced a person's identity development, and the shaded ovals with colored borders depict salient identities within a particular context or moment in time. The colored lines that move through unshaded spaces denote a participant's ongoing identity development outside of the contexts that she mentioned in her story. Further exploration and use of this organizational and identity mapping system might elucidate the potential usefulness of this method in tracking multiple, intersecting salient identities in people's stories.

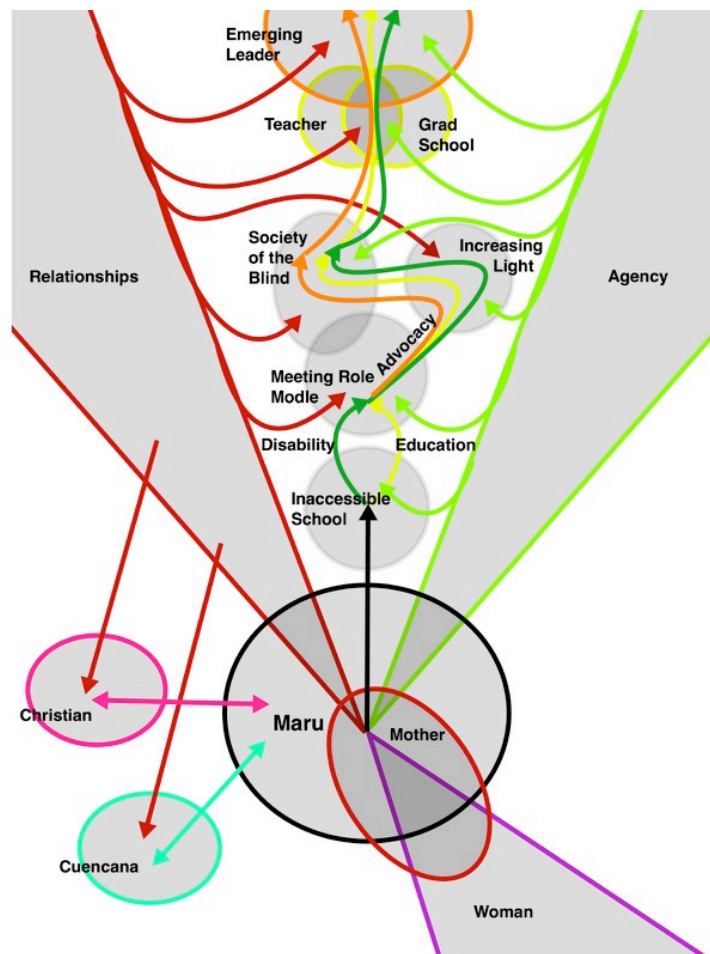
**LIZZIE IDENTITY MAP: ILLUSTRATES LIZZIE’S SALIENT, INTERSECTING IDENTITIES AS SHARED IN HER STORY**

Note. In these identity maps, the colored lines represent identities and how they moved and interacted with each other in a snapshot of a participant's identity story. The shaded ovals symbolize experiences or ecological contexts that influenced a person's identity development, and the shaded ovals with colored borders depict salient identities within a particular context or moment in time. The colored lines that move through unshaded spaces denote a participant's ongoing identity development outside of the contexts that she mentioned in her story. Further exploration and use of this organizational and identity mapping system might elucidate the potential usefulness of this method in tracking multiple, intersecting salient identities in people's stories.

## APPENDIX M

### MARU IDENTITY MAP: ILLUSTRATES MARU'S SALIENT, INTERSECTING IDENTITIES AS SHARED IN HER STORY

Maru had a core sense of self and described her various IDs as somewhat tangential, even the IDs shown here as developmental. Throughout her life, she drew from her relational values and sense of agency to enrich her IDs and experiences. Growing up, Maru's relationship with her mother organized her relational, agentic, and woman IDs. Maru also drew from IDs as a Christian and Cuencana. Maru traced the development of her disability, education, and advocate IDs in her story. She encountered an inaccessible elementary school and began to pursue her education from home; this generated her disability and educational IDs. When she was 12, Maru found a role model with a visual disability, which generated her advocacy ID. Maru's advocacy ID developed as she advocated for more light at home and increased her involvement in the Society of the Blind. Her disability, education, and advocacy IDs interacted as she pursued her education, taught children with visual disabilities, and advocated for change. At the time of our interviews, Maru was in the process of developing a leader ID.



Note. In these identity maps, the colored lines represent identities and how they moved and interacted with each other in a snapshot of a participant's identity story. The shaded ovals symbolize experiences or ecological contexts that influenced a person's identity development, and the shaded ovals with colored borders depict salient identities within a particular context or moment in time. The colored lines that move through unshaded spaces denote a participant's ongoing identity development outside of the contexts that she mentioned in her story. Further exploration and use of this organizational and identity mapping system might elucidate the potential usefulness of this method in tracking multiple, intersecting salient identities in people's stories.

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